University of Alberta

Reproductive Decision-Making in the Context of HIV/AIDS in Kabarole Region of Western Uganda

by

Jennifer Marie Heys ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master of Science
in
Global Health

Department of Public Health Sciences

Edmonton, Alberta
Fall 2007

Library and
Archives Canada

Published Heritage
Branch

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque et
Archives Canada

Direction du
Patrimoine de l'édition

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 978-0-494-33258-0
Our file Notre référence
ISBN: 978-0-494-33258-0

NOTICE:
The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:
L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

Canada

To my parents,
for their unending support,
and for instilling within me the desire to explore the world
and connect with all of it's inhabitants

Abstract

This study examined the reproductive decision-making process of HIV positive and HIV negative men and women in Kabarole Region of western Uganda. The main research question explored the effect of an HIV diagnosis on the desire to stop childbearing. Quantitative and qualitative methods were utilized: the quantitative portion consisted of semi-structured interviews (n=421) and the qualitative portion consisted of six focus group discussion sessions and one unstructured interview (n=43). The quantitative data was analyzed using descriptive, univariate and multivariate techniques and the qualitative data was analyzed using thematic analysis.

The odds of wanting to stop childbearing were 12.3 times greater for HIV positive individuals than for HIV negative individuals (95% CI: 2.7-54.8, p=0.001). However, we found there are many barriers that exist for people of Kabarole region with respect achieving their fertility desires. Thus, the desire to limit or stop childbearing may be unattainable for many HIV positive individuals.

Acknowledgements

First and foremost I wish to thank my thesis supervisor, Dr. Walter Kipp, for his guidance and support of my project. Your willingness to share with me your second home of Fort Portal and expertise of western Uganda was invaluable for both the success of the thesis project and my personal development as a student, researcher, traveler and human being. Thanks also to my supervisory committee, Dr. Duncan Saunders and Gian Jhangri. Dr. Saunders, your contribution the thesis was invaluable and your willingness to organize my defense was most appreciated. Gian Jhangri, thank you for your patience and for turning the arduous task of analyzing my data into an important educational experience. I would also like to thank my external examiner, Dr. Amy Kaler, for her valuable input. The project would not have been possible without generous funding support from the Fund for the Support of International Development Activities (FSIDA) and the Canadian Institute of Health Research (CIHR).

I would like to acknowledge the Community Based ARV Project staff in Fort Portal for their in-country support. Tom, thank you for doing everything in your power to ensure the project ran as smoothly as possible. Regina, Gorretti and Jimmy, thank you for helping with logistics and administration and putting up with my demands in the office. Edward, your ability to move us place to place during the rainy season was impressive and much appreciated. A special thank you goes to Peter, my Ugandan father, for his immeasurable patience and support with the fieldwork portion of the project. To my research assistants, Sam, Rose, Janepher, Faridah, Colletta and Rose, thank you for your hard work and for helping me better understand the Ugandan culture. Our conversations on the journeys home from the field were most entertaining and enlightening!

I would also like to acknowledge the local community members and health care staff who were involved with the study. The project would not have been possible without the support of the staff of the Rwimi, Bigodi and Kibiito Health Centres (in particular, Kisembo, Grace, Deo, Carol, Claire, Benedict, Archibald, Dr. Wamala and Gertrude). Also invaluable were Mary and the CB-ARV project volunteers who acted as our spokespeople and liaisons with the communities. My deepest gratitude goes to the participants of the study. Your willingness to discuss personal issues is so much appreciated. I hope that any benefits that result from this study will find their way to your local health centres and communities. I will never forget the kindness, generosity and welcoming attitude of the Ugandan people.

I wish to also acknowledge my friends and family members who supported me along the way. In Uganda, this includes my roommates, Putu and Dax, for sharing in the fun times and providing support during the challenging times. As well, my dear friends Meghan, Juan Carlos, Andrew, Joris, Nikki, Eddie, Jamie, Rose, Alex and Agnes, thank you for sharing with me this special time in Uganda and I hope we will meet again in the future. Denise, Leslie and Kristen, thank you for your help editing the thesis manuscript. To my parents, Bev and Randy, and my sister, Stephanie, thank you for always believing in me and supporting my dreams no matter how farfetched or impractical they are!

Table of Contents

Chapter 1: Introduction……………………………………………………..1

1.1 Purpose of the study……………………………………………………...2

1.1.1 Research questions……………………………………………....2

1.1.2 Background……………………………………………………...2

1.2 Literature review……………………………………………………......... 4

1.2.1 Reproductive decision-making in general…………………… 4

1.2.2 Reproductive decision-making in the context of HIV/AIDS…10

1.2.3 Barriers to achieving fertility desires…………………………18

1.2.4 Ethics and policy……………………………………………...19

1.3 Methodology……………………………………………………………..21

1.3.1 Study design………………………………………………………..21

1.3.2 Study location and timeframe…………………………………...21

1.3.3 Semi-structured interview questionnaire…………………….. 23

1.3.4 Focus group discussion question guide……………………… 26

1.3.5 Study sample……………………………………………………27

1.3.6 Ethical considerations……………………………………….... 30

1.3.7 Data collection………………………………………………….. 33

1.3.8 Data analysis……………………………………………………34

1.3.9 Dissemination activities…………………………………………38

Chapter 2: Results – Semi-structured Interviews……………………….. 39

2.1 Participation status…………………………………………………….....39

2.2 Sample population…………………………………………………….. 40

2.2.1 Age………………………………………………………………….41

2.2.2 Socioeconomic status……………………………………………42

2.2.3 Education……………………………………………………….. 43

2.2.4 Religion…………………………………………………………….44

2.2.5 Ethnicity……………………………………………………………45

2.2.6 Number of children………………………………………………..45

2.3 Descriptive and univariate analysis…………………………………… 48

- 2.3.1 Desire for children.......... 48
- 2.3.2 Partner communication surrounding reproductive decisions... 51
- 2.3.3 Control over reproductive decisions.......... 53
- 2.3.4 Contraceptive behaviours.......... 54
- 2.3.5 HIV/AIDS characteristics.......... 58
- 2.3.6 Effect of HIV/AIDS on reproductive decision-making.......... 60
- 2.3.7 Knowledge regarding mother to child transmission of HIV... 64
- 2.3.8 Health services.......... 67
- 2.4 Univariate and multivariate analysis.......... 68

Chapter 3: Results – Focus Group Discussions.......... 72

- 3.1 Categories.......... 72
  - 3.1.1 Childbearing in general.......... 73
    - 3.1.1.1 Factors that promote childbearing.......... 73
    - 3.1.1.2 Factors that limit childbearing/family size.......... 77
    - 3.1.1.3 Cultural norms.......... 79
    - 3.1.1.4 Reproductive decision-making process.......... 83
  - 3.1.2 Family planning.......... 85
    - 3.1.2.1 Norms.......... 85
    - 3.1.2.2 Barriers.......... 88
  - 3.1.3 HIV/AIDS in general.......... 95
    - 3.1.3.1 Testing.......... 95
    - 3.1.3.2 Treatment.......... 97
  - 3.1.4 Childbearing and HIV/AIDS.......... 98
    - 3.1.4.1 Influence of HIV diagnosis on reproductive decisions. 98
    - 3.1.4.2 Challenges/concerns.......... 103
    - 3.1.4.3 Interventions.......... 105
    - 3.1.4.5 Stigma/discrimination.......... 109
- 3.2 Themes.......... 110
  - 3.2.1 Women's lack of control.......... 110
  - 3.2.2 Changing norms.......... 112

Chapter 4: Discussion.......... 114

Validity of the study.. 114
Fertility desires in general.. 114
Effect of HIV/AIDS on fertility desires..116
Reproductive decision-making process.. 117
Family planning use.. 119
HIV testing..124
Knowledge – strengths and gaps... 126
Service provision.. 128
Stigma and discrimination... 129
Chapter 5: Conclusions and Recommendations................................. 131
5.1 Key Findings..131
5.2 Recommendations..132
5.3 Study Strengths..133
5.4 Study Limitations...133
5.5 Future Directions... 137
5.6 Conclusions...138
References... 139
Appendices.. 144
Appendix A – Visual Representation of the Study Area........................... 144
Appendix B – Semi-structured Interview Questionnaire............................145
Appendix C – Questions for Focus Group Discussion Sessions.................. 153
Appendix D – Invitation Letter for Field Recruitment............................... 159
Appendix E – Invitation Letter (participant not present)........................... 160
Appendix F – Invitation Form for Clinic Recruitment...............................161
Appendix G – Invitation Letter for Focus Group Discussion Sessions......... 162
Appendix H – Information Letter for Interviews..163
Appendix I – Consent Form...165
Appendix J – Information Letter for Focus Group Discussion Sessions........166
Appendix K – Frequency Data from Interviews...168
Appendix L – Univariate Analysis of Interview Data by HIV Status and Sex.179

List of Tables

Table 1.3.3: Test-Retest Results for Selected Interview Questions.....................26

Table 2.1.1: Non-participation by Recruitment Site..39

Table 2.2a: Univariate Analysis of Socio-Demographic Variables by HIV Status. 40

Table 2.3.6: Responses to Attitude Questions – Is it okay for HIV positive couples to become pregnant under certain conditions?.. 63

Table 2.3.7a: Responses to questions about whether or not mother to child transmission of HIV is possible under different birth delivery and anti-retroviral treatment conditions.. 65

Table 2.3.7b: Responses to questions about how many children would be infected if ten HIV positive mothers gave birth under different conditions............ 66

Table 2.4: Univariate and Multivariate Values for Logistic Regression Model with Desire to Stop Childbearing as the Dependent Variable................. 69

List of Figures

Figure 2.2.1: Respondents by Age Group………………………………………….. 41

Figure 2.2.2a: Interview Participants by Occupation…………………………….....42

Figure 2.2.2b: Percentage of Interview Participants Who Own Certain Items……… 43

Figure 2.2.3: Education Level of Interview Participants……………………………44

Figure 2.2.4: Interview Participants by Religious Affiliation……………………… 45

Figure 2.2.6a: Interview Participants by Number of Pregnancies……………………46

Figure 2.2.6b: Interview Participants by Number of Living Biological Children……47

Figure 2.2.6c: Interview Participants by Number of Non-Biological Children…….... 48

Figure 2.3.1a: Response to the question "Do you want (more) children?"…………..48

Figure 2.3.1b: Average # Desired Children by Subgroup……………………………49

Figure 2.3.1c: Participants Reasons for Wanting to Stop Childbearing……………...50

Figure 2.3.1d: Participants Reasons for Wanting to Continue Childbearing………... 50

Figure 2.3.2: Do couples know their partner's fertility desires?............................... 53

Figure 2.3.4a: Methods of Choice for Current Contraceptive Users………………... 56

Figure 2.3.4b: Reasons for Using Current Method of Contraception……………….. 57

Figure 2.3.4c: Reasons for not Currently Using Contraception…………………….. 57

Figure 2.3.6a: Reasons given for why couples where the wife is HIV positive can still become pregnant…………………………………………………….... 63

Figure 2.3.6b: Reasons given for why couples where the wife is HIV positive should not become pregnant……………………………………………………. 64

Abbreviations and Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-Retroviral Drugs
ART	Anti-Retroviral Treatment
CD4+ count	Number of CD4+ Helper T-cells per 1mm^3 of Blood (used to determine strength of an individual's immune system)
DHS	Demographic and Health Survey
FP	Family Planning
HAART	Highly Active Anti-Retroviral Treatment
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
ICPD	International Conference on Population and Development (Held in Cairo in 1994)
IUD	Intra-Uterine Device
LC1	Local Council 1 (village-level administrative unit)
MTCT	Mother to Child Transmission
OC	Oral Contraceptive
PMTCT	Prevention of Mother to Child Transmission
RDM	Reproductive Decision-Making
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TBA	Traditional Birth Attendant
TFR	Total Fertility Rate
VCT	Voluntary Counseling and Testing

Chapter 1: Introduction

The decision whether or not to have children is often complex and influenced by many factors. Such factors include number of prior children, economic considerations, opinions of partner/family members, social structure and availability of contraceptive services and supplies. HIV positive individuals have additional considerations to take into account when deciding whether or not to have children. These include the possibility of passing the virus from mother to child and the likelihood that one or both parents could die prior to the child reaching adulthood (Newell et al, 2004). Furthermore, HIV positive women may be less fertile and may be more likely to experience adverse maternal outcomes (French & Brocklehurst, 1998, Lewis et al, 2004). Regardless of these barriers, many people still elect to reproduce after receiving an HIV diagnosis for various personal, cultural and economic reasons (Gregson et al, 1998). While the evidence that HIV/AIDS reduces women's fertility is quite convincing, the relative contributions of social, biological and behavioral factors have not been fully elucidated (Fabiani et al, 2006, Ross et al, 1999).

Overall evidence from Africa as to whether or not HIV influences reproductive decision-making (RDM) is mixed. Some studies have shown that an HIV diagnosis causes people to choose to have fewer children; however changes in fertility are generally small and the desire to limit childbearing is often limited to those who already have children (Allen et al, 1993, Feldman & Maposhere, 2003, Grieser et al, 2001). Other research has shown that HIV/AIDS does not have a marked impact on fertility decisions, particularly for those who do not show signs or symptoms of disease (Gregson et al, 1998, Baylies, 2000, Rutenberg et al, 2000). These studies have been conducted in various countries, however there have been few studies which have specifically studied the effect of HIV diagnosis on reproductive decision-making in Uganda as of yet. Uganda may differ from other countries, given the extremely high fertility rate and aggressive efforts to reduce HIV transmission. These two conditions conflict, as high fertility suggests low contraceptive use and cultural demands to produce many offspring, whereas declining HIV prevalence suggests a strong desire to reduce transmission.

1.1 Purpose of the study

The purpose of this study is to elucidate the factors that influence the people of Kabarole region, western Uganda, with respect to their reproductive decisions. It also examines if and how an HIV diagnosis influences reproductive desires, behaviours and the decision-making process. Specifically, we investigate the effect of an HIV diagnosis on the desire to stop childbearing. Finally, it explores barriers which exist for individuals in Kabarole region with respect to realizing their fertility desires and goals.

1.1.1 Research questions

This study explores the following questions:

1) What factors influence reproductive decision-making for the people of Kabarole region, western Uganda?
2) If and how does an HIV diagnosis affect reproductive-decision making for the people of Kabarole region?
3) Do HIV positive individuals in Kabarole region have a greater desire to stop childbearing than HIV negative individuals?
4) What barriers restrict individuals in Kabarole region from realizing their reproductive goals?

1.1.2 Background

Uganda is a country that is currently experiencing high levels of both HIV/AIDS and fertility. It was one of the first countries affected by HIV/AIDS in the early 1980's. The HIV prevalence peaked in 1990-1992 when up to 30% of the population was infected in the major urban centres (Kilian, 2002). However, the adult prevalence of HIV/AIDS in Uganda has declined by 79% since the early 1990s and is presently 7% (Ministry of Health Uganda, 2005). There are many reasons for this decline, most of which were due to strong political support from President Yoweri Museveni. A multi-sectoral response was orchestrated by the Ugandan AIDS Commission and supported by various Non-Governmental Organizations (NGOs) which not only reduced the HIV prevalence but also decreased stigma associated with the disease. In the former

Kabarole District (which now includes Kabarole, Kamwenge and Kyenjojo Districts) the Basic Health Services Project was established in 1988 by the German Agency for Cooperation (GTZ) in partnership with the Ugandan Government. HIV/AIDS programs were implemented that led to a significant decline in seroprevalence of HIV, increased knowledge of HIV prevention methods, increased condom use and delayed sexual debut (Kilian, 2002).

In contrast, family planning programs have never been a priority for the Ugandan Government. President Yoweri Museveni remains convinced that a large population is key to economic success in Uganda even though it has been shown that the massive population growth rate of 3.4% per annum is fuelling poverty (Wakabi, 2006). Museveni cites China as an example of how a large population can contribute to economic growth while ignoring the fact that large family sizes are driving his country's citizens into poverty due to land fragmentation and asset shortages as well as by putting strain on health, education and water/sanitation services (Wakabi, 2006). The main driver of population growth in Uganda is the high total fertility rate (TFR) which has remained steady at approximately 7 (6.9-7.1) from 1998 until 2002 (Anonymous, 2004). Uganda's TFR remains one of the highest in the world: the only countries with higher fertility rates are Niger, Guinea Bissau and Mali (Wakabi, 2006). The TFR in Kabarole District is even higher than the national average (TFR=8.0).

Although the HIV prevalence has decreased drastically it still remains quite high at 7% of the adult population of Uganda (Ministry of Health Uganda, 2005). Since the epidemic is generalized and the predominant mode of transmission is heterosexual contact, females of reproductive age have the highest rates of HIV infection (Ntozi et al, 1997). Therefore, Kabarole region is an area where both HIV infection and pregnancies occur frequently, and where many women are affected by both conditions. This is problematic because HIV positive women face higher risks of pregnancy complications and miscarriages/stillbirths than HIV negative women and also may transmit the disease to their child.

1.2 Literature Review

A literature search was conducted using Medline, CINHAL, Web of Science and Global Health databases as well as the Cochrane Library. Search terms and keywords included various combinations of the following: "HIV", "reproduction", "pregnancy", "family planning", "decision-making", "Africa", "Uganda", "AIDS", "pregnancy decisions", "fertility", "fertility intentions", "reproductive decisions" and "reproductive planning". Articles were cross-referenced in order to find additional literature on these topics. Only studies conducted on sub-Saharan African populations have been included in this analysis since the social context and the interventions available to reduce mother to child transmission (MTCT) of HIV differ widely around the world.

1.2.1 Reproductive Decision-Making in General

Reproductive decision-making is a process by which an individual or a couple determines whether or not to have children. Thus, it is not just the final fertility desires and intentions that are important, but also which factors have influenced the decision-making process. Fertility desires and intentions can be assessed by asking respondents direct questions, such as their ideal number of children/family size or whether they would like to continue or stop childbearing. Key fertility behaviours, including contraceptive use, sexual activity and/or decision to carry a pregnancy to term, are also used to assess fertility intentions (Hagewen & Morgan, 2005). However, it is important to note that lack of contraceptive use is not necessarily an accurate indicator of intention to reproduce in Uganda, as the unmet need for contraception in Uganda is up to 60% (Blacker et al, 2005, Lutalo et al, 2000). Furthermore, carrying a pregnancy to term is also not always a good indicator as abortion services are often illegal or very difficult to obtain in sub-Saharan Africa and sexual activity may be coerced or forced. Sometimes actual pregnancy or fertility is measured as an indicator; however this may not reflect the end result of a decision-making process as unintended pregnancy often occurs. This section describes the factors that influence reproductive decision-making in Africa irrespective of HIV-related issues.

Age

A study conducted in the Rakai district of Uganda in 1998 showed that the mean number of desired children reduced by age. For women aged 15-19 years 3.9 children were desired, compared to 4.5 for women aged 20-29 years, 5.6 for women aged 30-39 years and 6.2 for women aged 40-49 years (Lutalo et al, 2000). A similar trend was seen when the fertility desires of men were examined by age. Dodoo et al (1998) suggest that although young respondents may be further from their reproductive goals they are often more accepting of modern contraception and less traditional.

Sex

A study conducted in the Rakai district of Uganda in 1998 showed that men desired larger families than women (Lutalo et al, 2000). In the Masaka and Lira districts of Uganda couples participated in a study where they were interviewed individually about their desire to stop childbearing. The findings of this study showed that more women than men wished to cease childbearing (37.6% women vs. 29.6% men) (Wolff et al, 2000). The effects of these differences in desired family size will be discussed further in the section on control over reproductive decisions.

Marital Status

A study conducted in Rakai district of Uganda found that being married was a predictor of current contraceptive use for pregnancy prevention in a survey of respondents who had been sexually active at some point in their lives, however frequency of current sex was not controlled (Lutalo et al, 2000). It is likely that married/cohabitating individuals will have more frequent sex and that they are also more likely to be attempting to conceive. Divorce or death of a spouse can cause fertility intentions to change or to be put on hold until another partner is found.

Parity

The 2000/2001 Uganda Demographic and Health Survey (DHS) showed that high parity women are more likely to want to stop childbearing and to be using contraception than low parity women (Anonymous, 2004). However this survey also showed that women of higher parity have a higher mean ideal number of children (6.0) than women of low parity or those who have not yet had any children (4.1). High parity was found to be a predictor of contraceptive use for pregnancy prevention in various studies (Bankole et al, 1996, Lutalo et al, 2000). Survey results from a study of RDM in couples by Wolff et al (2000) in the Masaka and Lira districts of Uganda showed that both women's and men's desire to stop childbearing increases with increasing parity, although the increase is steeper for women than for men. Thus, individuals of higher parity tend to want a greater number of total children but may be closer to their reproductive goals, and thus are more likely to use contraception and wish to stop childbearing.

Area of Residence

The 2000/2001 Uganda DHS showed that the total fertility rate was 4.0 for urban residents and 7.4 for rural residents (Anonymous, 2004). Urban women were almost twice as likely to be current users of modern contraception (46.3% urban users versus 19.3% rural users). The extent to which this finding reflects fertility intentions is unknown, as urban residents may have greater access to modern contraceptives. This was shown in a study of RDM in couples by Wolff et al (2000) in the Masaka and Lira districts of Uganda which found that for couples where both partners wished to stop childbearing the unmet need for contraception was 22% in urban areas and 66% in rural areas. Thus, it may be more difficult for rural residents to attain their fertility desires.

Education

In the 2000/2001 Uganda DHS it was shown that the total fertility rate for women with no schooling and primary schooling only are 7.8 and 7.3 respectively, whereas the total fertility rate for women with secondary or higher level schooling is 3.9 (Anonymous, 2004). This survey also showed that contraceptive use varied by education status: 13% for those with no schooling, 21% for those with primary schooling and 49% for those with secondary or higher level schooling. Education was found to be a predictor of contraceptive use for pregnancy prevention in studies conducted in Uganda and in Kenya (Lutalo et al, 2000, Njogu, 1991). Wolff et al (2000) found that for both men and women, those with lower educational attainment felt that they had less control over their reproductive decisions.

Economic Concerns

In the Rakai district of Uganda focus group discussions identified the most common positive attribute of contraception to be its ability to facilitate "good upbringing of children" due to parents' improved ability to provide them with education and nutrition (Lutalo et al, 2000). In a study of RDM carried out in the Masaka and Lira districts of Uganda economic reasons were most often cited as the main reason for wanting to cease childbearing, and men were more likely than women to give this response (Wolff et al, 2000).

Economic concerns have likely increased due to the HIV/AIDS epidemic, where adult morbidity and mortality is high. The cost of caring for sick relatives and for raising a child alone in the event of spousal death result in economic hardships that increase the economic burden on families.

Infant/Child Mortality

High infant/child mortality tends to beget high fertility. Studies on sub-Saharan African populations have consistently shown that living in an area of high child mortality and/or personally experiencing child death increases fertility (Fitaw et al, 2004, Gyimah & Fernando, 2002, Kimani, 2001, Nebie et al, 2001). This may occur by use of either the insurance and/or replacement strategies. The insurance strategy entails having more children than desired in anticipation that some will die and those who remain will approximately equal the preferred number of children. The replacement strategy involves conceiving a child to replace one who deceased previously. Uganda's infant mortality rate is high (79 per 1000 live births) as is it's under five mortality rate (136 per 1000 live births) (United Nations Children's Fund, 2005). In fact, only 27 countries in the world fare worse than Uganda with respect to mortality in children aged five years or less (United Nations Children's Fund, 2005). Furthermore, the situation is not improving: Ssewanyana and Younger (2005) found after controlling for individual, community and household determinants that there is no discernable trend in infant mortality in Uganda. Thus, it is likely that infant mortality is a driver of high fertility in Uganda.

Social/Religious/Cultural Norms

In Africa a common expectation of marriage is that the woman will have children (Feldman & Maposhere, 2003). In Uganda, children are regarded as members of the paternal clan which contributes to the social obligation of women to bear children, regardless of their HIV status (Lutalo et al, 2000). Since having children is an extremely important social expectation, women and couples may continue childbearing to avoid social stigma or isolation even when they are HIV infected or destitute. Women are often defined by their ability to bear children and a very high value is placed on fertility. Women who are infertile may feel inadequate and be divorced by their husbands. In 2003 Chacko examined adolescents' desire for children in Kabarole district and found that having children was an extremely important aspect of their futures (Chacko, 2004).

A study of RDM with couples in the Masaka and Lira districts of Uganda revealed that friends, family members and village leaders may be consulted if disagreements arise with respect to childbearing (Wolff et al, 2000). As a result, reproductive decisions are largely shaped by the culture of the community in which individuals reside.

Control over Reproductive Decisions

There is evidence that RDM is not always a joint effort, and that women usually defer to men in these matters. This was shown in a Ghanaian study from 1988 in which wives' attitudes to contraception were significantly affected by their husbands' characteristics, while husbands' attitudes to contraception were generally independent of their wives' characteristics (Ezeh, 1993). Wolff et al (2000) asked male and female participants in their study conducted in the Masaka and Lira districts of Uganda if they agreed with, disagreed with or had no opinion about the following statement: "The number of children that I will have with my partner depends mostly on what my partner and others want, not what I want". Overall, women were more than twice as likely as men to agree with this statement, indicating that men had more power than women over reproductive decisions. However 25% of men agreed with the statement, indicating that male control over RDM is not absolute. This study also found that modern contraceptive use in women who wished to discontinue childbearing dropped dramatically when male partners wished to continue childbearing. In contrast, male contraceptive use did not alter depending upon partner opposition.

It is quite common for women use covert contraception when their partner is opposed (Kipp, 2006). When this is the case, women tend to utilize methods that are easily concealed, such as injectable hormonal contraceptives. The 2000/2001 DHS showed that in Uganda injectable contraceptives are the most commonly used method (Anonymous, 2004).

There are multiple reasons why the fertility intentions of the male partner often triumph over those of the female. Firstly, the core of African society is the ancestral lineage and descent, which emphasizes the lineage bond over the conjugal tie. Thus, marriage frequently brings together a woman and a man that have a stronger allegiance to their lineage kin than to each other. The marriage contract is centered on the payment of bride wealth from the groom's family to the bride's family that compensates the bride's family for her future births who become a part of the groom's lineage, which shifts RDM to the male side (Dodoo, 1998). Secondly, the gendered nature of the division of labor in African society also contributes to men's dominance in reproductive decision-making (Dodoo, 1998). Women are dependent upon their partners financially and cannot refuse them or they may be abandoned and left destitute. Thus, men control the balance of power in most relationships.

Communication

Even when men and women concur with respect to their fertility desires these ideals are often not achieved due to a lack of effective communication surrounding reproductive decisions. For example, a qualitative study by Feldman et al (2003) revealed that very few women had discussed family planning with their husbands. One respondent was quoted as saying "We never talked about family planning. I just got pregnant."

Survey results from a study of reproductive decision-making in couples by Wolff et al (2000) in the Masaka and Lira districts of Uganda showed that only 42% of women and 46% of men had discussed stopping childbearing with their partner and that there was not always agreement within a couple as to whether or not this type of discussion had occurred. Sixty-four percent of women and 84% of men reported knowing their partners fertility intentions without ever having openly discussed the subject. Further questioning showed that many men and women obtain information about their partners' fertility intentions through indirect and nonverbal channels rather than through direct conversation. Thirty-five of women and 40% of men assumed their partners fertility desires based upon presumed characteristics of "all men" or "all women". On the other end of the spectrum, 15% of women and 5% of men reported not knowing their partners fertility intentions despite having discussed them. This suggests that for those who did discuss reproductive intentions the communication process was not always effective. This study also showed that the likelihood of having discussed stopping childbearing increased with increasing parity for both men and women. Focus group discussions revealed that most people believed that the likelihood of discussing fertility intentions would be greater in urban and well-educated couples than in rural and less-educated couples. It was further revealed that proposing an end to childbearing could come at a high social price as it may raise suspicions of infidelity and children outside the union. This lack of discussion is disconcerting, as the data also showed that those who did not openly discuss their reproductive desires tended to assume that their partner wanted to have more children when they actually did not. About one in three people were not aware of their partners' desire to stop childbearing, and this discrepancy was largely narrowed by discussion of fertility intentions.

1.2.2 Reproductive Decision-Making in the Context of HIV/AIDS

There has been much debate surrounding the impact HIV/AIDS has and will have on fertility in sub-Saharan Africa. While it is now accepted that fertility is reduced in those who are HIV infected for biological and physiological reasons, the impact of a diagnosis on desire for children is not well understood (Ross et al, 1999). Evidence has been offered which supports each of the following theories: HIV/AIDS increases intention to reproduce, HIV/AIDS decreases intention to reproduce and HIV/AIDS has no effect on intention to reproduce.

Evidence that HIV/AIDS Increases Intention to Reproduce

Setel et al (1995) propose that the HIV/AIDS epidemic will increase fertility as HIV positive individuals may attempt to accomplish unmet reproductive goals knowing that they will not live a normal life span. It has also been hypothesized that HIV/AIDS could increase fertility in endemic areas where infant and child mortality is high if couples decide to replace deceased children (replacement strategy) or have more children than they desire due to fears that some of children will not survive (insurance strategy) (Grieser et al, 2001, Ntozi et al, 1997, Tuladhar, 1985). Thus, the high rates of stillbirths, spontaneous abortion and infant and neonatal mortality in HIV infected women could reduce contraceptive use or could reduce or eliminate culturally prescribed periods of abstinence, thereby increasing fertility (Setel, 1995).

A study conducted in Burkina Faso which measured the effect of prenatal HIV testing on subsequent pregnancy showed that the only predictor of the occurrence of a pregnancy after HIV diagnosis was the poor outcome of the previous pregnancy (stillbirth, infant death) (Nebie et al, 2001). This information supports the replacement theory, however it is important to note that the same study also showed a poor rate (18%) of test-sharing with partners, which suggests that for many couples the HIV diagnosis would not have been taken into account during the decision-making process.

Seven percent of respondents stated in a study by Grieser et al (2001) that HIV/AIDS caused people in their community to have more children than they normally would have to ensure that some would survive. While this supports the insurance strategy, it must be noted that four times as many respondents thought that HIV/AIDS causes people to limit childbearing.

Overall, the research has shown that use of the insurance and replacement strategies is limited in response to the HIV/AIDS epidemic and that while certain individuals may increase childbearing as a result of the epidemic this tendency is not shared by the majority.

Evidence that HIV/AIDS Reduces Intention to Reproduce

It has also been suggested that HIV positive individuals or couples will wish to limit childbearing following their diagnosis, thus leading to a decrease in fertility. There are many reasons for this, most involving concerns for the health of either the mother or the child. This can involve fears of complications or death of either the mother or child during pregnancy or childbirth as well as the concern that children will be orphaned. In the case of orphans, the parents may fear for the well-being of the child and also for the relatives or friends who will step in to look after the child following their deaths.

Fears relating to maternal health may become more pronounced, and desire to raise children may decrease, as AIDS disease progression occurs. These fears are justified, as a systematic review to investigate the effect of pregnancy on disease progression and survival in women infected with HIV found that there does appear to be a weak association between adverse maternal outcomes (death, HIV disease progression, progression to an AIDS defining illness and drop in CD4+ count to below 200×10^6/L) and pregnancy (French & Brocklehurst, 1998). Furthermore, this review also showed that HIV progression in pregnancy was significantly more common in developing country settings than in developed countries. The association between maternal HIV infection and perinatal outcome was investigated in a systematic review and meta-analysis performed by Brocklehurst et al (1998). This analysis showed that spontaneous abortion, stillbirth, perinatal mortality, infant mortality, intrauterine growth retardation, low birth weight, and pre-term delivery were all significantly associated with maternal HIV infection. Sensitivity analyses showed that the association between infant mortality and maternal HIV infection was stronger in studies conducted in developing countries than in those conducted in developed countries.

A Burkina Faso study found advanced stage of HIV infection significantly associated with a reduction of subsequent pregnancy in pregnant women who were informed of their HIV status; however this may be due to biological reasons (Nebie et al, 2001). A Tanzanian study found that HIV infected women were more likely to be using contraception than uninfected women (Hunter et al, 2003).

Feldman et al (2003) performed a qualitative study of Zimbabwean women in HIV support groups to learn more about the impact of HIV/AIDS on their sexual and reproductive lives. Virtually all women wished to either stop or limit childbearing following their diagnosis. Those who wished to stop childbearing generally had children already, and wanted to give priority to them. Many of these women used dual protection to avoid future pregnancies. Women who still wished to have children had either no living children or no children from their current relationship. These women recognized the risks involved, but these were outweighed by their desire for a child. Five of the seven women with wanted pregnancies had already lost babies to AIDS, yet all got pregnant again. Some wanted a child for themselves whereas others wanted a child to please their partner or to compensate them because they had paid lobola (bride price). These feelings were not mutually exclusive. None of the women wanted many children, but instead wanted to simply give birth to and raise one healthy child, which is much less than the average fertility rate for Zimbabwe. This study showed that a women's desire to have children after an HIV diagnosis varied according to their personal situation. Young childless women wanted to have a limited number of children regardless of their HIV status, while HIV provided an added incentive to women with several children to stop childbearing.

Grieser et al (2001) performed a qualitative study in Zimbabwe to assess the impact of HIV/AIDS on RDM in a situation where over 25% of the population was infected but almost no one knew their serostatus. Results of this study indicate that although childbearing is still extraordinarily important from a cultural point of view it is now becoming more acceptable to limit the number of children to a much lower number than in past years. The impact of HIV/AIDS on childbearing was mixed. Approximately half of the participants stated that HIV/AIDS caused them to limit their childbearing, 20% stated that HIV/AIDS had no effect on reproductive decision-making and 7% stated that HIV/AIDS caused people to have more children than they ordinarily would to ensure that some survive (26% of respondents did not state their opinion on this topic). The most frequently cited reason for limiting childbearing due to HIV/AIDS was the fear and emotional pain of child death. Most respondents stated that they would not continue childbearing if one of their children died of AIDS. This does not seem to hold true for those who do not have a child or for those who do not have a child from their current relationship, as it was also shown that having a child is important in securing the bond between husband and wife and that the fear of transmitting HIV is less than the fear of dying without a child.

Evidence that HIV/AIDS Does Not Affect Reproductive Decision-Making

An alternate hypothesis is that HIV/AIDS will have no effect on fertility. One reason for this view is the importance of rearing children in African culture. For example, in Uganda, children are regarded as members of the paternal clan which contributes to the social obligation of women to bear children, regardless of their HIV status (Lutalo et al, 2000). Thus, women and couples may wish to continue childbearing to avoid social stigma or isolation. Furthermore, women who test positive for HIV may be unlikely to disclose their status to their partner due to fear or divorce or abuse (Nebie et al, 2001). Continuing to bear children may be the only way for a woman to hide her diagnosis from her partner and from others in the community, especially in areas where the stigma associated with HIV/AIDS is great. It also allows her to maintain a semblance of her former life, before receiving the diagnosis.

A study conducted in Rakai District, Uganda in 1998 showed that HIV serostatus had no effect on overall contraceptive use, although a greater proportion of HIV infected women reported using condoms than uninfected women (a finding of borderline significance) (Lutalo et al, 2000). The fact that overall contraceptive use did not change depending upon HIV serostatus indicates that HIV infected women were not disproportionately trying to achieve or avoid future pregnancies. For men, there was no association between condom use and HIV serology.

The Burkina Faso study found that informing male sexual partners about their HIV seropositivity and using contraceptives had no influence on the occurrence of new pregnancies after the HIV diagnosis, nor did socio-demographic factors (Nebie et al, 2001). Thus, the pregnancy incidence for HIV positive women who had received voluntary counseling and testing (VCT) remained comparable with the pregnancy rate in the general population. The study also showed a poor rate of HIV test sharing with partners and a poor use of contraceptive methods despite regular advice and counseling.

In the qualitative study conducted by Grieser et al (2001) 20% of respondents stated that HIV/AIDS had no impact on their reproductive decisions. Their main reasons for this revolved around their opinion that Zimbabweans do not consider mortality when they make pregnancy decisions and that economic and other factors matter much more in the decision-making process.

Allen et al (1993) found in their study of a Rwandan VCT clinic that the incidence of pregnancy within two years of diagnosis was significantly lower for HIV positive individuals than for HIV negative individuals. However, the authors felt that this difference not necessarily attributable to the VCT process but was instead due to differences in fertility and sexual behaviours between HIV positive and HIV negative individuals, especially since the difference between the two groups was small. They also suspected that some newly diagnosed individuals decided to have children as a coping strategy which allowed them to maintain a sense of normalcy and return to their pre-HIV life.

Two studies from Kabarole District have outlined the importance of childbearing for women in spite of their positive HIV serostatus: In 1994 one study identified women of childbearing age and followed them up (Kipp et al, 2001). After one year, five out of the seven were pregnant, in spite of intensive counseling; in 2003 Chacko examined opinions of adolescents about their desire for children. Most of them said that being HIV infected would not deter them becoming pregnant (Chacko, 2004). These results would advocate that HIV infection does not significantly influence childbearing decisions of women in this region.

Perception of Risk of Mother to Child Transmission

If the mechanism and risk of mother to child transmission (MTCT) is not well understood the impact of an HIV diagnosis on reproductive intentions may be affected. The 2000/2001 DHS found that 83% of Ugandans surveyed knew that HIV can be transmitted from mother to child (Anonymous, 2004). Those with higher educational attainment were more likely to know this to be true. However, when asked about means of transmission, 58% of women and 53% of men think it can during pregnancy, 69% of people think it can occur during delivery, and 46% of women and 43% of men think it can occur during breastfeeding. Only 34% of women and 28% of men thought that MTCT could occur through all three routes. Thus, although most citizens were aware that MTCT is possible, only a minority of the population truly understands all of the mechanisms by which transmission occurs. This has also been shown in other studies of sub-Saharan African populations (Igwegbe & Ilika, 2005).

A qualitative study performed by Grieser et al (2001) in Zimbabwe revealed that all respondents knew about the risks of transmitting HIV through pregnancy and breastfeeding however these risks were greatly overestimated. Participants generally believed that all children born to HIV positive women would die of AIDS. Thus, healthy children were said to indicate the health of the parents in this region, where HIV testing was not readily available. This meant that if a child survived to age five the parents would continue to bear children as they believed themselves to be free of the virus.

One other misconception is that HIV positive women cannot become pregnant. This view was found to be held by focus group participants who participated in a study conducted by Kipp et al (2002) in Kabarole District. This misconception could cause unplanned pregnancies among HIV infected women if they forgo contraception, believing it to be unnecessary.

Effect of Anti-Retroviral Therapy

Concerns regarding maternal and child health may be alleviated to some degree when ART is available as maternal health will improve and the chances of passing the virus to the child will decrease dramatically. However, studies from the developed world show that even when all interventions to reduce MTCT are employed there is still a small risk of transmission (Foster & Lyall, 2006, Thorne & Newell, 2003). Even when ART is available in the developing world other interventions, such as breast milk substitutes and cesarean delivery, are often not accessible. Yet there have been reports from sub-Saharan Africa that people believe that ARV treatment alone reduces the chance of MTCT to zero. This misconception is dangerous it may cause those undergoing treatment to believe that their children are guaranteed to not contract HIV.

Views of Community Members and Health Care Workers

Community members and health care workers may have negative views of HIV positive women who become pregnant, which may in turn influence peoples' reproductive behaviours. For example, women may choose to not become pregnant due to fears that they will be ostracized or reprimanded by others. Alternatively, they may hide their diagnosis from the community or from health care workers to avoid discrimination or avoid seeking medical attention for their pregnancy.

Feldman et al (2003) found during a qualitative study conducted in Zimbabwe that although most women who had been pregnant at or since their HIV diagnosis felt they had been well treated during antenatal/maternity care about one quarter of those interviewed felt that they had not received proper care because of their HIV status. Many women did not disclose their HIV status to health workers in family planning clinics and maternity units in order to avoid discrimination. One woman said that she did not receive proper care when she gave birth because the health workers were all afraid of being infected with HIV. Others reported being scolded or criticized by health care workers for getting pregnant following their HIV diagnosis. Overall, 80% of the HIV infected women in the survey felt that society expected HIV positive women not to be sexually active. A South African study stated that clinic staff reported cases where health care workers avoided patients who they suspected to be HIV positive (Sherr et al, 2003).

1.2.3 Barriers to Achieving Fertility Intentions

Unmet Need for Contraception

In Uganda the National Population Policy for Sustainable Development was introduced in 1995 (Blacker et al, 2005). This document emphasizes demographic change to improve the quality of life and standard of living of the country's citizens (Lutalo et al, 2000). However, the 2000/2001 Uganda DHS results showed that although the total fertility rate was 6.9 the desired family size was less than this number for women of every age and parity, ranging from 4.1 in the youngest age group to 6.4 in the oldest age group (Anonymous, 2004). It was also shown in a study conducted in the Rakai District of Uganda in 1998 that women of all ages desired fewer children than they actually had, suggesting an unmet need for contraception (Lutalo et al, 2000). There was a relatively low rate of modern contraceptive use in Uganda of only 18.2% in 2000–2001 and an unmet need for contraception of about 60% (Anonymous, 2004, Blacker et al, 2005, Lutalo et al, 2000). This is believed to be largely due to the fact that the National Population Policy was introduced much later than similar legislation in other developing countries and that family planning for unmarried individuals was not supported by the Ministry of Health until following the International Conference on Population and Development in Cairo in 1994 (Blacker et al, 2005). Thus, access was denied to adolescents and to single, divorced or widowed individuals until this time. Furthermore, since the legislation is relatively new, access is still limited in many remote regions of the country and barriers to use may exist. These barriers may include fear of side effects, cost, non-confidentiality of services, partner opposition, concerns regarding effectiveness, and cultural or religious factors. Partner opposition is sometimes overcome through covert contraceptive use (Biddlecom & Fapohunda, 1998, Wolff et al, 2000). However, women may be wary of utilizing this strategy since it is not uncommon for wives who are believed to be infertile to be divorced or stigmatized. If access contraceptives are limited, as is often the case in sub-Saharan Africa, this can be a hindrance to those who wish to alter their reproductive intentions following an HIV diagnosis.

Discrimination Due to HIV Status

As discussed above, Ugandans often have more children than they wish due to cultural pressures and an unmet need for contraception. Alternatively, it is also possible that individuals/couples have fewer children than they wish. This situation most likely occurs when the female partner is HIV positive. This may result from an inability to conceive or to carry the pregnancy to term. It could also result when stigma and opposition from health care workers or community members inhibit HIV infected women from acting on their desire to become pregnant.

The misconception of 100% transmission often encourages women to have a child to either determine their serostatus or to deflect suspicion of their HIV diagnosis. These situations occur especially in areas where testing is unavailable and/or stigma is high. Thus, children who may not have been desired under normal circumstances are being deliberately conceived.

1.2.4 Ethics and Policy

The ethics and policy surrounding childbearing in women diagnosed with HIV is complex. Wesley et al (2000) state that the Centre for Disease Control recommended in 1985 that HIV positive women delay childbearing, and that this recommendation has not yet been modified. This is surprising, given the recent interventions to reduce MTCT including treatment with antiretroviral drugs such as Zidovudine and Nevirapine, delivering by cesarean section and using breast milk substitutes.

In contrast, the Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS states the following in their International Guidelines on HIV/AIDS and Human Rights: "Laws should be enacted to ensure women's reproductive and sexual rights, including the right of independent access to reproductive and STD health information and services and means of contraception, including safe and legal abortion and the freedom to choose among these, the right to determine the number and spacing of children, the right to demand safer sex practices…" (United Nations, 1998).

The International Conference on Population and Development (ICPD) held in Cairo in 1994 states that: "…people… have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant. These rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. In the exercise of this right, they should take into account the needs of their living and future children and their responsibilities towards the community. To enable and support responsible voluntary decisions about child-bearing and methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law and to have the information, education and means to do so. Governments should develop policies and guidelines to protect the individual rights of and eliminate discrimination against persons infected with HIV and their families." (United Nations, 1994). While this declaration supports every individual's right to reproduce according to their desires, it also acknowledges that they must be supplied with education to make informed choices and health care services to achieve the highest possible standard of health. Furthermore, individuals are expected to consider the needs of their future children, which may conflict with their desire to have more children in the case where the female is HIV infected.

The overall impression from the literature is that people must be provided with education so that they can make informed decisions about childbearing. They also must receive health care services, including a variety of contraceptive options and access to all possible measures to prevent MTCT. However, the right of an individual to decide whether or not to have children is their own and must be protected.

1.3 Methodology

1.3.1 Study Design

This study utilized both quantitative and qualitative methods to address the research questions. The quantitative component consisted of a cross-sectional survey of two groups of individuals: those who have tested HIV positive and those who have tested HIV negative. The qualitative component included six focus group discussion sessions and one in-depth interview. Each focus group involved specific groups of individuals: a) HIV-positive women, b) HIV-positive men, c) HIV-negative women, d) HIV-negative men, e) health care workers, f) HIV-positive women who have become pregnant following their diagnosis. As well, one unstructured qualitative interview was performed with a health care worker from the study area.

1.3.2 Study Location and Timeframe

The semi-structured interviews were conducted from October 10 – December 7, 2006 in Kabarole, Kamwenge and Kasese Districts of western Uganda. The focus group discussions were conducted in late November of 2006 in Kabarole and Kamwenge Districts after the majority of the interviews had been completed.

Participants were recruited from three trading centres: Rwimi and Kibiito in Kabarole District and Bigodi in Kamwenge District. Rwimi is a semi-urban centre at the site of a major traffic route and is located approximately 30 km south of Fort Portal, which is the capital city of Kabarole District. Since Rwimi is very close to the district border, some of the patients at the health centre are from the northern region of Kasese District even though Rwimi Trading Centre itself is within Kabarole District. Kibiito is a smaller centre off the same road as Rwimi about 20 km south of Fort Portal and 10 km north of Rwimi. Bigodi is about the same size as Kibiito and is about 30 km south-east of Fort Portal along a different road than Rwimi and Kibiito. This road is unsurfaced and less traveled than the one that serves the other two centres. Whereas Rwimi and Kibiito are within Kabarole District, Bigodi is in Kamwenge District. Since Kamwenge District used to be part of Kabarole District and the area where the study took place will be termed Kabarole Region even though it includes Kamwenge District and the northern region of Kasese District as well as Kabarole District. For a visual representation of the study area see Appendix A. It is important to note that while the health centres are based in the trading centres along the major roads the majority of the study participants live in the surrounding villages (rural areas) and access the trading centres when they require health care or other services.

The cross-sectional survey included semi-structured interviews with clients from three sites in Kabarole Region: the Health Centre III in Rwimi, the Health Centre III in Bigodi and the Health Centre IV in Kibiito. All of these health centres are government-run and the number refers to the type of staff and services offered at the location. A designation of 'health centre V' represents a hospital that is staffed by multiple physicians and can support a wide range of services including surgeries. Health centre IVs are usually run by a physician and support less services than a hospital where health center IIIs offer even fewer services and usually employ a Clinical Officer (approximately equivalent to a nurse practitioner or a medical assistant) as the in-charge. Thus, the clinics from which the study participants were drawn offer services such as VCT, health education, PMTCT, distribution of various prescription drugs, immunization and outpatient services. However, they are limited in terms of inpatient facilities and do not routinely perform surgeries. The Rwimi and Kibiito Health Centres offer ARV drug distribution programs whereas the Bigodi health centre does not and patients from this region travel large distances to access these services elsewhere. The HIV positive participants were drawn from all three recruitment cites: Rwimi Health Centre, Bigodi Health Centre and Kibiito Health Centre. In contrast, all of the HIV negative participants came from the Rwimi Health Centre.

1.3.3 Semi-Structured Interview Questionnaire

The semi-structured interview questionnaire contained 83 questions; however each participant was asked only 38-69 of these questions because prior responses determined what was subsequently asked of each participant. The questionnaire took 30-40 minutes to administer including the process of obtaining informed consent.

The questionnaire obtained socio-demographic information, including age, sex, parity, religion, education and economic status, from all participants. Economic status was determined by assessing housing quality and ownership of various items, such as radios, animals, bicycles, cars and land.

Next, reproductive desires and the process of reproductive decision-making was assessed by asking questions about additional children desired, reasons for wishing to continue or cease childbearing, who maintains control over RDM, and extent to which individuals communicate with their partner regarding reproductive decisions. Current and ever use of contraceptives was then determined for all participants and information was sought about covert contraceptive use and barriers to contraceptive use.

Following this, the HIV-related questions were asked. These questions were asked after the childbearing questions in order to reduce social desirability bias that might result when someone who is known to be HIV positive feels it would be perceived poorly if they expressed interest in having children. The HIV-related questions included those that assessed the respondent's serostatus, their partner's serostatus, and disclosure of serostatus to their partner. Participants were also asked if any of their family members died of AIDS or if they knew any children under age 10 who died of AIDS in order to determine if experience of AIDS death influences fertility desires. The HIV positive individuals were then asked questions about whether or not they were on ART or had experienced AIDS-related symptoms or illness as disease progression could greatly affect reproductive decisions. They were also asked if their diagnosis had an effect on their fertility desires and if they/their partner had become pregnant following their diagnosis. The HIV negative individuals were asked questions to determine if and why their fertility desires would change as a result of an HIV diagnosis. All participants were then asked questions to assess their perception of risk of vertical transmission for HIV positive women who are either on or off ARV treatment and who deliver either in the villages or at the hospital/health unit. Finally, all interviewees were asked their opinions about HIV positive individuals having children. At the end of the questionnaire participants were invited to share any concerns, thoughts or feelings they had which were recorded in the "comments" section. A copy of the questionnaire can be found in Appendix B.

Translation and pre-testing of questionnaire

The questionnaire was initially developed in Edmonton during the research proposal stage. Changes were made upon arrival in Uganda after consultation with local experts in the health department and the research assistants who would be administering the questionnaire. It was then translated into the local language, Rutooro, and then back into English by a different translator for linguistic reliability. The two English versions were compared and all discrepancies were identified and corrected.

The questionnaire was then pre-tested on seven individuals who tested for HIV at the Rwimi Health Centre but were not eligible to participate in the study. This exercise was conducted to determine if the questions were being understood and if the desired answers were being obtained. Modifications were made to the questionnaire based upon the pre-testing exercise.

Slight changes were made to the questionnaire as the study progressed through the data collection phase. These modifications included adding questions that were not previously recognized as being necessary as well as clarifying certain questions by adding a prompt (in two occasions) and changing a word (on one occasion). These modifications were all performed early in the data collection phase. As a result, sometimes data is available only for a subset of the interview participants who were administered the questionnaire after a new question was added.

Reliability

The reliability of the questionnaire was assessed by test-retesting 26 participants and calculating the percent agreement of the responses. Respondents who were willing and chosen to participate in the test-retest were administered the questionnaire twice in the same location and by the same research assistant exactly seven days apart. The respondents who were test-retested were mostly HIV-positive and were drawn from all three of the recruitment sites (Rwimi, Bigodi and Kibiito). Convenience sampling was used to select the test-retest participants, about half of whom were retested early on in the study and the other half near the end of the study.

Percent agreement was obtained by determining the percentage of questions that were answered in the same manner for both applications of the questionnaire. To determine this, each question was given a score of "0" (responses were not the same), "0.5" (responses were partially the same) or "1" (responses were exactly the same). An example of a "0.5" score would be when a respondent identifies "peasant/farmer" as their occupation on one application of the questionnaire and "peasant/farmer and housewife" the other time the questionnaire was administered. If a question was asked only during one application of the questionnaire it was not included in the test-retest analysis. Only questions that were to be evaluated quantitatively were assessed: for the most part, this included questions where the responses were yes/no, a number or a predetermined category.

The overall percent agreement for the questionnaire was 92.4% for all participants. The percent agreement for each individual participant varied from 83.3% to 100%. The percent agreement for each question varied from 66.7% to 100% (for questions that were retested 10 times or more). Test-retest results for some of the most substantive questions are shown in the following table:

Table 1.3.3: Test-Retest Results for Selected Interview Questions

Question	# Times Retested	% Agreement
What is your age?	26	100%
What is your occupation?	26	84.6%
What is your highest level of education?	26	88.5%
What is your religious affiliation?	26	96.2%
What is your tribe?	26	100%
How many children have you given birth to/ fathered?	26	84.6%
Are you the primary caregiver for any children that you have not given birth to/fathered?	26	96.2%
Would you like to have (more) children?	26	96.2%
Have you or your partner ever used contraception?	26	96.2%
Are you or your partner currently using contraception?	25	84.0%
Which method(s) of contraception are you currently using?	19	92.1%
Have you ever wanted to use contraception and not been able to?	26	96.2%
Have you ever experienced any AIDS-related symptoms/illness?	25	92.0%
Are you taking antiretroviral treatment?	25	96.0%

1.3.4 Focus Group Discussion Question Guide

The purpose of the focus group discussion sessions was to clarify and expand on the themes and topics discussed during the interviews. Thus, the questions are similar to those asked during the interviews, although they were sometimes more specific to a particular issue or more general to attempt to capture the views of the population of the area rather than the individuals themselves. In order to ensure that all pertinent subjects were included the focus group discussions the questions were compiled shortly before these sessions took place. Cultural appropriateness of the questions was discussed with the focus group facilitator prior to the sessions and minor changes were made. Questions not in the interview guide were also sometimes asked during the focus groups if certain answers led the researcher to new ideas or concepts not previously considered. As well, probing questions were asked during the sessions if more information about a particular topic was sought. The questions differed depending upon the group of individuals in the session and the list of questions for each of the focus groups can be found in Appendix C. At the end of each focus group the participants were invited to ask questions or provide comments about any aspect of health to the researcher or the focus group facilitator, who was a trained Clinical Officer.

The duration of each focus group discussion session varied from 40 minutes to two hours depending upon the amount of discussion of the questions and the willingness of the participants to donate their time to the project. All of the sessions were conducted in Rutooro by the focus group facilitator with the exception of the health worker group which was conducted by the researcher in English.

1.3.5 Study Sample

Subject Inclusion and Exclusion Criteria

All of the interview participants were required to have tested for HIV and received their test results. This ensured that only those who were counseled regarding their test results were interviewed. As well, potential participants for the interviews were excluded if they were not currently cohabitating with a partner of the opposite sex, between 18-44 years of age and/or if they were bedridden, due to the fact that these individuals were less likely to be currently considering childbearing. The inability to communicate confidently in either the Rutooro or English language was also a reason to exclude potential participants as these were the languages in which the research assistants were fluent.

All participants were required to be living in Kabarole, Kamwenge or Kasese District. This maintained the uniformity of the sample population by excluding individuals who tested while visiting Kabarole Region but resided in different locations. This also facilitated ease of data collection by ensuring that participants and/or research assistants did not have to travel large distances in order to conduct interviews. Data collection was further simplified by requiring a village-level (LC1) address for each research participant as attempting to locate an individual within a larger area was unfeasible.

As the individuals who made up most of the focus group discussion participants were those who had been interviewed previously the same inclusion and exclusion criteria applies for most of the focus group participants. The exception to this is the health care worker focus group: individuals of any sex, marital status and health status were eligible to participate provided they were currently employed as a health care worker in the Kabarole Region and were over 18 years of age. The participants in focus group session f) had to have become pregnant after finding out that they were HIV positive.

Sample Selection

The HIV positive individuals who were eligible to participate in the study were all those who ever tested positive at the Rwimi and Bigodi Health Centres and met the subject inclusion and exclusion criteria. As well, any HIV positive individual who was on the ARV treatment program at the Kibiito Health Centre and met the inclusion and exclusion criteria was recruited into the study. HIV testing had been conducted since January 16, 2006 in Rwimi, for about 2 years prior to the data collection for this study in Kibiito and for about 3 years in Bigodi, and all of the patients who tested during these timeframes were eligible. Partners of research participants who lived within the project area and met the eligibility criteria were deemed suitable to participate; even their HIV test had been conducted at an alternate location.

All HIV negative women who tested at the Rwimi Health Centre between October 18 and December 6, 2006 on a Monday, Tuesday, Wednesday or Friday and met all the study criteria were eligible to participate. Individuals who tested on Thursdays were not recruited because of scheduling conflicts and the fact that very few people come for testing on this day as it is primarily an immunization day at the health centre. There were a few exceptions to this schedule: participants were not recruited on October 30, November 10 or November 13 because HIV testing was not conducted on these dates for various reasons. As well, participants were not recruited on November 20 because a scheduling conflict prohibited the research team from being present at the clinic.

HIV negative men included those identified in the same manner as the HIV negative women; however this did not yield enough research participants. As a result, all men who tested negative at the Rwimi Health Centre since the VCT program was initiated on January 16, 2006 were included in the sample, not only those who tested during the time-frame of the study. As well, HIV negative males who were the spouse of an interview participant were also eligible to participate in the study even if they had tested in a different location. Note that no sampling techniques were utilized for recruitment of any of the interview participants; rather all those deemed eligible were invited to partake.

Purposive and convenience sampling were used for the focus group discussion sessions. For the HIV positive women, HIV negative women, HIV positive men and HIV negative men focus group sessions individuals were chosen if they were easily located and/or if their interview responses were deemed interesting by the investigator. For ease of travel, they all were living within the Rwimi area and had been originally recruited through the Rwimi Health Centre which is where these focus group sessions took place. For the focus group with HIV positive women who became pregnant following their diagnosis all of the individuals who were recruited through the Bigodi Health Centre and met the criteria for the session were invited. This session was held in Bigodi for two reasons: to hear the views of individuals living in a different recruitment area and to obtain the desired number of participants as very few women from the Rwimi site had become pregnant following an HIV diagnosis (likely due to the fact that testing had been occurring in Bigodi for a much longer time than in Rwimi). All staff members of the Rwimi Health Centre were invited to participate in the health care worker focus group discussion session. The participants included two clinical officers, two enrolled nurses (one of whom was also a trained VCT counselor), one health assistant and two nursing assistants (one of whom was also a microscopist). In addition, one impromptu unstructured interview was held with a health care worker from Fort Portal because this individual had knowledge on the topics of interest and was willing to participate.

Sample Size

The cross-sectional survey included semi-structured interviews with 421 participants: 199 HIV positive and 222 HIV negative. According to the sample size calculation, 198 individuals were required in each group to be able to detect a difference of 10% between the two groups if the response rate is low (10% or less) and a difference of 15% if the response rate is high (50%), with alpha = 0.05 (two-tailed) and beta = 0.20. Up to ten individuals were invited to each focus group discussion session although not all attended. In the end each focus group consisted of between five and nine participants. In total 43 individuals participated in the qualitative portion of the study.

1.3.6 Ethical Considerations

Approval of study

The study was approved by the researcher's Thesis Committee (Dr. Walter Kipp and Dr. Duncan Saunders) and the University of Alberta Health Research Ethics Board in Edmonton. Upon arrival in Uganda, the study was also approved by the Uganda National Council for Science and Technology in Kampala, and the Ugandan Ministry of Health via the Kabarole District Director of Health Services. Approval was also obtained from the in-charge officer of each of the health units from which research participants were recruited prior to the commencement of the study in each area.

Recruitment and Enrollment

All of the HIV positive participants were recruited from their homes at least one week after receiving their test results. The HIV negative men who tested before the study began were also recruited from their homes. Community volunteers aided the research team in finding potential participants in their village. In Rwimi the community volunteers were those involved as volunteers with the Community-Based ARV project at the Rwimi Health Centre. In Bigodi the community volunteers were the in-charge of the Bigodi Health Centre and the Bigodi Post Test Club leader, whereas in Kibiito the volunteer was a nursing assistant at the Kibiito Health Centre. In the case where a community volunteer was not available or did not know some of the individuals on the recruitment lists the village-level politician (LC1 chairman) was asked to help locate potential participants. All of these individuals knew their communities well and tended to be respected leaders in their respective villages.

Once the community volunteer led the research assistant to the potential participant's home the research assistant read a short introduction to the individual and determine if they met the study inclusion and exclusion criteria (Appendix D). The potential participant was then asked if they were interested in participating in the study. If they responded affirmatively they were asked if they would prefer the interview be conducted in their home, the local health centre or at another location. Only once the respondent was alone in this location with the interviewer was HIV/AIDS mentioned as being part of the study: until this time the potential participants and volunteers were told only that it was a study about childbearing. This was necessary to protect participants from stigma they might have faced if we revealed to others that they were recruited because they tested for HIV/AIDS. All interviews were completed in the presence of only the participant, research assistant and sometimes the researcher. Partners of participants were not permitted to be present during the interviews both to protect the confidentiality of the participant as well as to improve data quality since their presence may have influenced their partners' responses to the interview questions. If the participant was not home a letter was left explaining in both English and Rutooro that they were eligible to participate in a research study about childbearing and could come to the health centre within a certain time-frame should they wish to participate (Appendix E).

HIV negative women and men who tested during the timeframe of the study were recruited at the health centre immediately after they received their HIV test results and post-test counseling. A form was administered by the VCT counselor at the end of the post-test counseling session to determine if the individual was eligible for the study and interested in participating (Appendix F). Eligible and interested individuals were sent to the research team and the interview was conducted in a private area of the health centre.

Those who completed the interview were asked if they were willing to participate in a focus group session. They were told that their HIV serostatus would be made known to the other participants of the focus group (except for the session with health care workers) and that participation was voluntary. Those who were interested and selected to participate in a focus group session were approached one week prior to the session by a research assistant at either their home or the health centre. They were asked once again if they were comfortable sharing their serostatus with others and discussing HIV/AIDS and childbearing issues in a group setting. If they agreed to participate and were available for the session they were given a letter and asked to arrive at the health centre at a specific date and time (Appendix G). The local health centres were chosen as the sites for holding the discussions since they were private, neutral and easily accessible for all participants. It should be noted that almost all of the interview participants were willing to also attend a focus group session even knowing that their HIV status would be revealed, indicating that HIV-related stigma in the project area was quite low.

Informed Consent

Prior to the interview an information letter was read to each participant in the language of their choice: English or Rutooro (Appendix H). Following this, individual informed consent was obtained from all participants by the research assistant (Appendix I). Respondents were free to refuse to answer any questions they were not comfortable with or to terminate the interview at any point.

All focus group participants were informed individually and privately before the session that their HIV serostatus would become common knowledge to the rest of the focus group participants and that involvement was completely voluntary. If they still elected to participate they were read an information letter about the content session and informed consent was obtained (Appendix J and I). Participants were free to leave the session at any point and to not answer questions if they were uncomfortable.

Confidentiality

Study participants were given an identification number and all questionnaires and focus group transcripts identify the participants only by these numbers and never by name.

Name-number associations are maintained only by the researcher and will not be disclosed to anyone aside from the co-investigators. All documents or presentations of the data identify the study participants only by identification number or socio-demographic information. Hard copies of data are locked in a secure location in Fort Portal and will be destroyed five years following the completion of the study.

Possible Adverse Effects

To our knowledge, no adverse physical effects were resulted from this research. The telephone number of a social worker was available in case participants experienced emotional distress during the data collection process, however this situation never occurred.

Remuneration

Research participants were reimbursed their transport expenses if they traveled from their home to the health centre or another location to complete the interview or focus group discussion session. Interview participants were offered a small gift following their interview to thank them for their participation. The monetary value of each gift was very small (about 200 Ugandan Shillings or 10 Canadian cents). Similarly, focus group participants were offered food and drinks valued at approximately 1000 Ugandan Shillings or 50 cents Canadian for their participation at the end of the focus group session. As the participants were not told about these gifts in advance and the monetary value of was minimal it is unlikely that they influenced anyone's decision to participate.

1.3.7 Data Collection

Research team and training

The researcher was provided with expertise from Dr. Walter Kipp and Dr. Duncan Saunders in the fields of International Health, HIV/AIDS and Epidemiology. Field supervision in Kabarole District was provided by Tom Rubaale (Community-Based ARV Project) and field support was provided by other members of the Community-Based ARV Project, especially Peter Rwakilembe. These individuals provided guidance and aided in the recruitment and selection of research assistants and study participants.

Four research assistants, one focus group facilitator, and one transcriber were hired in Uganda to assist with data collection and analysis. All of these individuals were fluent in both English and Rutooro and had some prior research experience. The research team was briefed on the purpose of the study and the data collection procedures. The research assistants provided input into the finalization of the questionnaire and were trained to administer the questionnaire in a specific manner to standardize the interview process and reduce interviewer bias. Role playing and pre-testing exercises improved the research assistants' understanding of how to administer the questionnaire prior to the commencement of the study. This training continued throughout the data collection process if any new questions or concerns arose. The interview data was verified each day by the researcher as it was not possible for her to attend each individual interview. During this process all responses were checked for unusual values and any discrepancies or omissions were discussed with the interviewer. In one case a research assistant was asked to return to a participant to clarify an answer.

Data Recording

Interview responses were recorded in pen by the interviewer on the questionnaire sheet itself during the session. All focus group discussions and the one in-depth interview were audio taped and transcribed verbatim. The in-depth interview and focus group conducted in English were transcribed by the researcher whereas those conducted in Rutooro were transcribed and translated by a local professional. Notes were written by the researcher during and immediately following these sessions to summarize the discussions and capture the tenor and mood of the participants and the dynamics of the group.

1.3.8 Data Analysis

Semi-structured interview data

All of the interview data was entered into Microsoft Access by the researcher in Uganda. Questionnaires were scanned and the hard copies left in a secure location in Fort Portal while the scanned copies were retained by the researcher. Data was transferred into Excel and STATA for statistical analysis upon arrival in Canada. These programs were used to analyze the data using descriptive, univariate and multivariate methods. For those individuals who were test-retested the data from the first time the questionnaire was administered was used for this analysis. Data from open-ended survey questions were coded by the researcher and analyzed using descriptive statistics.

Chi-squared and t-tests were used for univariate data analysis: t-tests (two-tailed, $\alpha=0.05$) were used for continuous variables that were normally distributed and chi-squared tests were used for categorical variables. Multivariate logistic regression analysis was performed to determine if the odds of wanting to stop childbearing were different for HIV positive and negative individuals. Logistic regression was used to model "desire to stop childbearing" as it is a variable with a binary outcome (yes/no). Univariate analysis was first performed to see if desire to stop childbearing was significantly associated with any of the variables that were of interest as potential predictors. These potential predictor variables included those relating to socio-demographics (e.g. sex, age, religion, occupation, education, living children) and those relating to HIV/AIDS (serostatus, partner serostatus, experience of AIDS symptoms, ARV treatment, partner disclosure, AIDS death in family, AIDS death of a child, MTCT understanding, attitude and content of VCT counseling). All of the variables with $p<0.2$ in the univariate analysis were evaluated as predictors in the multivariate model. Other variables that were considered to be very important predictors were also retained in the model. Variables that lost their significance in the multivariate model were removed unless they were deemed to be important based upon the literature.

Although each interview was conducted individually and participants were identified as individuals sometimes it occurred that both partners of a couple were interviewed. This information was recorded and for selected questions the responses between partners were compared and the percentage of discordant results reported. This was done to assess how well couples are communicating with respect to their reproductive decisions. In total, 69 couples participated in the study and were included in this analysis.

Aggregate variables were created for some indicators as described below. Housing quality variables were divided into low and high for each part of the structure (low: mud floor, mud/thatched walls and thatched roof, high: cement/concrete/wood floor, walls of permanent materials, metal roof). Participants were awarded one point for each high quality housing structure and then grouped according to low housing quality (0 points), medium housing quality (1 point) or high housing quality (2-3 points). Ownership of items was assessed on a five point scale. One point was awarded for each of the following items owned by the participant: bicycle, radio, poultry, animals, land. Participants were then categorized as owning two or fewer items, three items, four items or all five items. TV, motorcycle and car were not included because these were owned by very few participants.

Aggregate variables were also created to gauge participant's understanding of MTCT. The variable "MTCT risk understanding" was created to determine if participants understood that the risk of MTCT was not absolute, meaning sometimes HIV positive women produce infected children whereas other times they remain uninfected. This was carried out because some studies have shown people to believe that every child born to an HIV positive person will also be infected and have even used this concept in self-diagnosis: if the child does not die of AIDS within five years of birth the mother is said to be HIV negative (Grieser et al, 2001). Some of our interview questions asked the participants how many children would be infected if ten HIV positive mothers gave birth under various conditions. Any participant who gave an answer that was not zero or ten to one or more of the questions was said to understand the concept of MTCT risk. As well, the variable "ARV understanding" was created to determine if participants understood that being on ARVs reduced the chances of MTCT. Respondents were said to understand the impact of ARVs on MTCT if they consistently reported that ART of the mother reduced the chance of MTCT. The variable "MTCT understanding" was created to see how participants faired overall with respect to their knowledge of MTCT. Participants were given one point if they answered any of the "MTCT no ARV" questions in the correct range one point if they answered any of the "MTCT ARV" questions in the correct range. The correct range was defined as 1-5 children becoming

HIV infected if the mother was not on ARVs and 1-3 children becoming infected if the mother was on ARVs (regardless of birth location because it plays a smaller role in risk of MTCT). Participants who answered within the correct range one or more times were said to have high MTCT understanding and those who answered all questions outside the range were said to have low MTCT understanding.

All respondents were then asked if it is okay for HIV positive women to become pregnant under certain circumstances. If they responded affirmatively to any of these questions they were placed in the "yes" category for the "attitude" variable whereas they were put in the "no" category if they responded negatively to all of these questions.

Focus Group Discussion Data

Surface readings of all transcripts were first conducted to obtain a general impression of the data. The six focus group discussions and one in-depth interview were then analyzed using thematic analysis in the manner described by Rothe (Rothe, 2000). This entailed organizing the data into categories and then extrapolating overarching themes from the data. This content of these sessions was first coded into four main categories: childbearing in general, family planning, HIV/AIDS in general and HIV/AIDS and childbearing. Some information from the transcripts was excluded from the analysis, including explanatory conversations between the two interviewers, personal health questions asked by the participants that were not directly related to the topic of interest and introduction/concluding remarks. Each of the main four categories was broken down into between two and four subcategories. These subcategories were sometimes separated into sections when they contained a large amount of information. Overarching themes were derived by assimilating information from multiple categories supporting the same general concept. These themes were compared to those from the semi-structured interview questions to validate the study findings. Patterns of behaviour and implications were derived from the major themes of the data and reported as key findings and recommendations.

All of the transcripts were analyzed together, regardless of those interviewed in each session. Thus, the results described represent patients and health workers, men and women and HIV positive and negative participants. However, when views clearly differ between groups this is noted in the text.

1.3.9 Dissemination Activities

Preliminary findings were presented Fort Portal, Uganda in December of 2006 to members of the Kabarole District Health team, Institute of Public Health at Makerere University and Community-Based ARV Project. The study results were presented at the Public Health Sciences Student Seminar Series at the University of Alberta in March of 2007. A briefing paper for policy purposes will be sent to the Ministry of Health, Kabarole District Health Department in Uganda in the summer of 2007, following the thesis defence. An abstract has been submitted for the Canadian Conference on International Health to be held in Ottawa, Canada in November 2007. Pending approval from the Thesis Committee, the study will be submitted to a journal specializing in either HIV/AIDS or family planning for publication.

Chapter 2: Results – Semi-Structured Interviews

This chapter describes the responses captured by the semi-structured interviews. Frequencies are reported in Appendix K and univariate analysis by HIV status and by sex are reported in Appendix L.

2.1 Participation Status

Upon arrival in Uganda lists of eligible individuals were constructed for each recruitment site (except for those who were interviewed post-test at the Rwimi Health Centre). For those who were located and invited to partake in the study the participation rate was 92%.

However, it was often difficult to locate people from these lists and recruit them into the study. Table 2.1.1 shows the percentage of potential participants who were interviewed, those who refused to participate, those who were found and given a flyer but did not come to the clinic to be interviewed and those who could not be located and given a flyer. Note that all of the individuals recruited from the Rwimi Clinic were HIV negative and everyone recruited from the Bigodi and Kibiito sites was HIV positive. The majority of those recruited from the field in Rwimi were HIV positive; however some were HIV negative men. These men include those identified from the Rwimi Clinic records as well as the partners of women who were previously interviewed.

Table 2.1.1: Participation status by recruitment site

	Bigodi % (n)	Kibiito % (n)	Rwimi Clinic Recruitment % (n)	Rwimi Field Recruitment % (n)	All Sites % (n)
Participated	93% (26)	95% (70)	94% (183)	52% (142)	74% (421)
Refused	0% (0)	0% (0)	5.1% (10)	1.5% (4)	2.4% (14)
Flyer delivered but not interviewed	3.6% (1)	1.4% (1)	1.0% (2)	6.9% (19)	4.0% (23)
Not located and/or not given flyer	3.6% (1)	4.1% (3)	0% (0)	40% (109)	20% (113)

2.2 Sample Population

A total of 421 interviews were conducted with individuals who had tested for HIV. Of these respondents, 64% were female (n=270) and 36% were male (n=151). Participants were split almost equally with respect to HIV serostatus: 53% were HIV negative (n=222) and 47% were HIV positive (n=199). All HIV negative individuals were recruited from the Rwimi Health Centre, whereas HIV positive individuals were recruited 52% (n=103) from Rwimi, 35% (n=70) from Kibiito and 13% (n=26) from Bigodi. All of the women and the majority of the men had only one spouse, however 9% (n=14) of men had two wives and 1% (n=1) of men had three. In terms of marital status, 60% (n=254) of respondents were married, 39% (n=164) were cohabiting and 1% (n=3) were both married and cohabiting with different partners (for simplicity, marital status of these three individuals was coded as missing for further analysis). Univariate analysis of socio-demographic variables by HIV status is reported in Table 2.2a.

Table 2.2a: Univariate Analysis of Socio-Demographic Variables by HIV Status

Variable	Response	HIV+ (n=199)	HIV- (n=222)	p
Recruitment Site*	Rwimi	52% (103)	100% (222)	<0.001
	Bigodi	13% (26)	0% (0)	
	Kibiito	35% (70)	0% (0)	
Age§		34.2 ± 6.0	27.8 ± 6.6	<0.001
Sex *	Female	61% (122)	67% (148)	0.025
	Male	39% (77)	33% (74)	
Marital Status*	Married	55% (109)	66% (145)	0.032
	Cohabiting	45% (88)	34% (76)	
# Spouses*	One	96% (191)	97% (215)	0.632
	Multiple	4% (8)	3% (7)	
Occupation*	Farmer/peasant	66% (132)	83% (184)	<0.001
	Businessperson	13% (26)	7% (15)	
	Other	21% (41)	10% (23)	
Attended School*	Yes	82% (163)	85% (188)	0.445
Education*	None	18% (36)	15% (34)	0.805
	Lower Primary	31% (61)	32% (70)	
	Upper Primary	37% (74)	41% (90)	
	Lower Second. +	14% (28)	13% (28)	
Dwelling Floor*	Cement/concrete/wood	10% (19)	9% (20)	0.849
	Mud	90% (180)	91% (202)	
Dwelling Walls*	Permanent materials	9% (18)	12% (26)	0.372
	Mud/thatched	91% (181)	88% (196)	
Dwelling Roof*	Metal	91% (182)	85% (188)	0.0330
	Grass/thatched	9% (17)	15% (34)	
Car Ownership*	Yes	1% (1)	1% (2)	0.628
Radio Ownership*	Yes	75% (149)	86% (192)	0.002

TV Ownership*	Yes	1% (1)	2% (5)	0.130
Land Ownership*	Yes	80% (159)	92% (204)	<0.001
Bicycle Ownership*	Yes	33% (65)	50% (111)	<0.001
Animal Ownership*	Yes	56% (112)	59% (130)	0.637
Poultry Ownership*	Yes	62% (123)	77% (171)	0.001
Motorcycle Ownership*	Yes	3% (6)	3% (7)	0.935
Religion*	Catholic	46% (92)	37% (83)	0.032
	Protestant	38% (76)	36% (81)	
	Muslim	4% (8)	10% (22)	
	Other	12% (23)	16% (36)	
Religiosity*	> once a week	24% (47)	15% (34)	0.089
	Once a week	72% (144)	81% (180)	
	< once a week	4% (8)	4% (8)	
Tribe*	Mutooro	56% (112)	17% (38)	<0.001
	Mukiga	28% (56)	46% (101)	
	Mukonjo	2% (3)	20% (44)	
	Other	14% (28)	17% (38)	
# Pregnancies§		4.9 ± 2.7	4.3 ± 2.6	0.0203
Experienced Death of a Child?*	Yes	40% (80)	41% (92)	0.796
# Living children§		4.0 ± 2.5	2.9 ± 2.2	<0.001
Non-bio children?*	Yes	59% (118)	34% (75)	<0.001
# Non-bio children§		1.3 ± 1.2	0.70 ± 1.1	<0.001

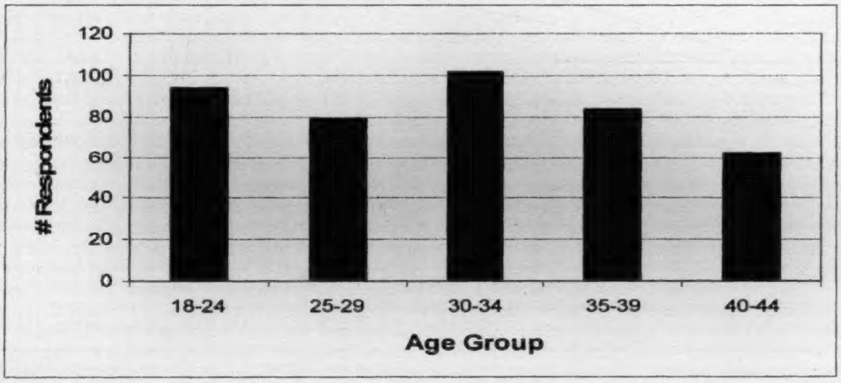
* indicates a categorical variable on which a chi-squared test was performed

§ indicates a continuous variable on which a t-test was performed (mean ± SD reported)

2.2.1 Age

The average age for all participants was 30.8 years. The age distribution of interview participants is shown in figure 2.2.1. The average age of men (33.7 years) was greater than for women (29.2 years) and the average age of HIV positive individuals (34.2 years) was greater than for HIV negative individuals (27.8 years). Both results were significant with p<0.001.

Figure 2.2.1: Respondents by Age Group

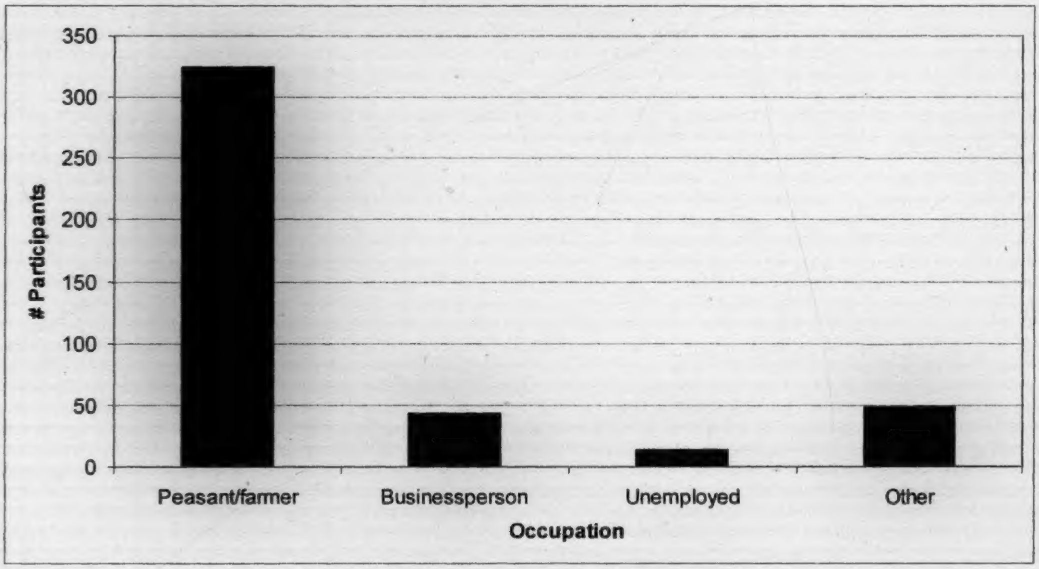


2.2.2 Socioeconomic Status

Socioeconomic status was assessed by collecting information regarding participants' occupations, housing quality and ownership of certain items. Income was not assessed as most participants were subsistence farmers and did not earn income from formal employment.

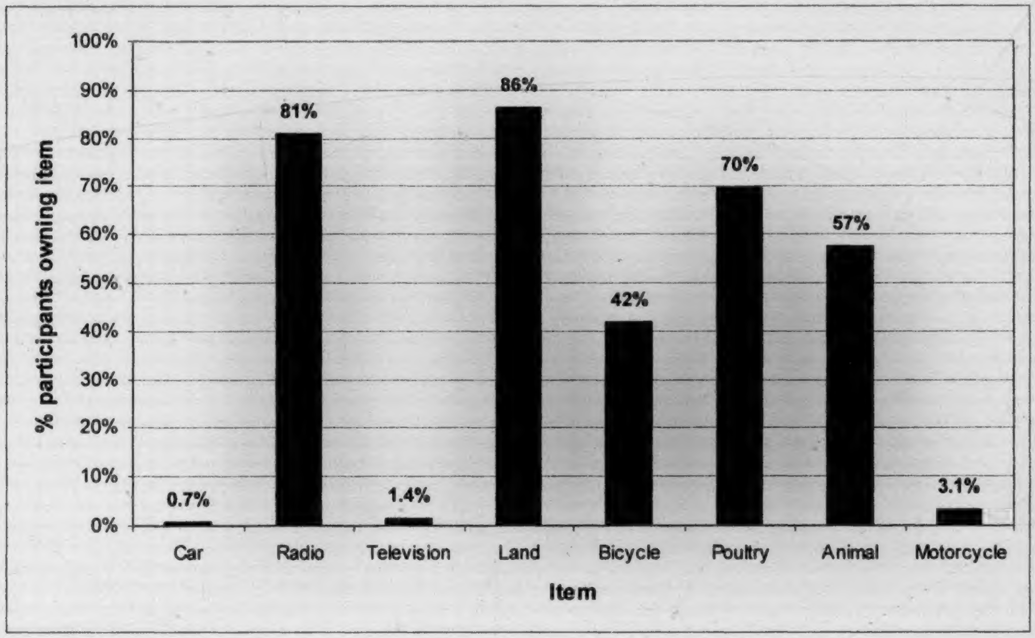
The research participants' occupations are summarized in figure 2.2.2a. Some participants had more than one occupation, thus the total number of occupations exceeds the total number of research participants. The occupations did differ by both HIV status (p=0.004) and sex (p=0.001). HIV negative individuals were more likely to be farmers whereas HIV positive participants were more likely to be businesspeople, unemployed or engaged in other occupations. Women were more likely to be farmers whereas men were more commonly employed as businesspeople or in other occupations.

Figure 2.2.2a: Interview Participants by Occupation



Most research participants lived in a mud house with a metal roof. In terms of the floor of the house, 91% (n=382) of respondents had a mud floor, 8.6% (n=36) had a cement floor and 0.7% (n=3) had floors made of other materials. Eighty-seven percent (n=368) of respondents had mud walls, 9.0% (n=38) had brick walls, 2.6% (n=11) had walls that were made out of mud mixed with sand and/or plaster and 1.0% (n=4) had walls that were made out of other materials. For the roofing materials, 88% (n=370) were made out of metal/iron sheets and 12% (n=51) were grass/thatched. The percentage of interview participants who owned certain items are shown in figure 2.2.2b.

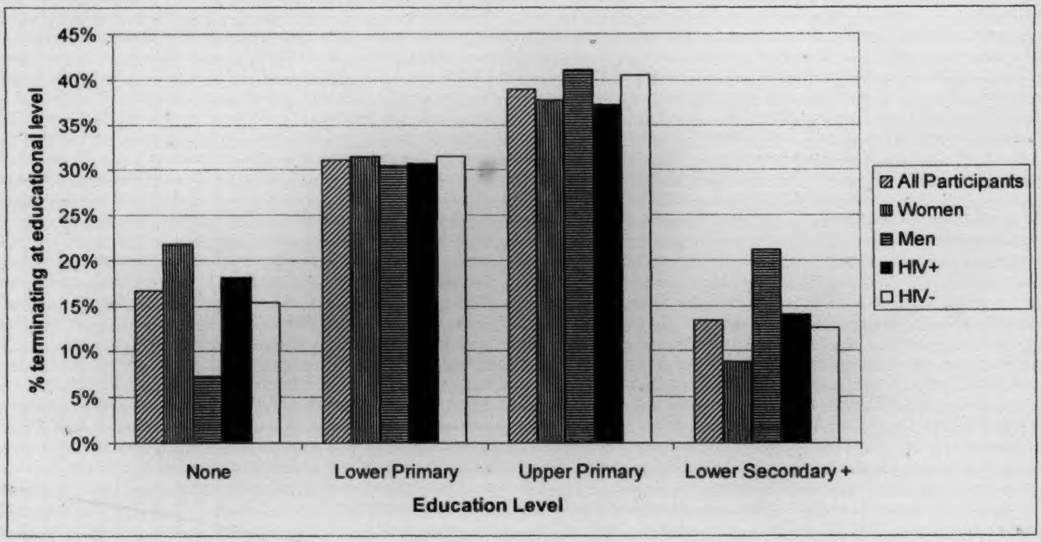
Figure 2.2.2b: Percentage of Interview Participants Who Own Certain Items



2.2.3 Education

Figure 2.2.3 shows the interview participants by their level of educational attainment. Most participants had primary level schooling with upper primary being the most common response followed by lower primary as the next most common response. Women tended to have lower educational attainment than men (p<0.001), however there was no difference when comparing the educational attainment of HIV positive and negative individuals (p=0.805).

Figure 2.2.3: Education Level of Interview Participants

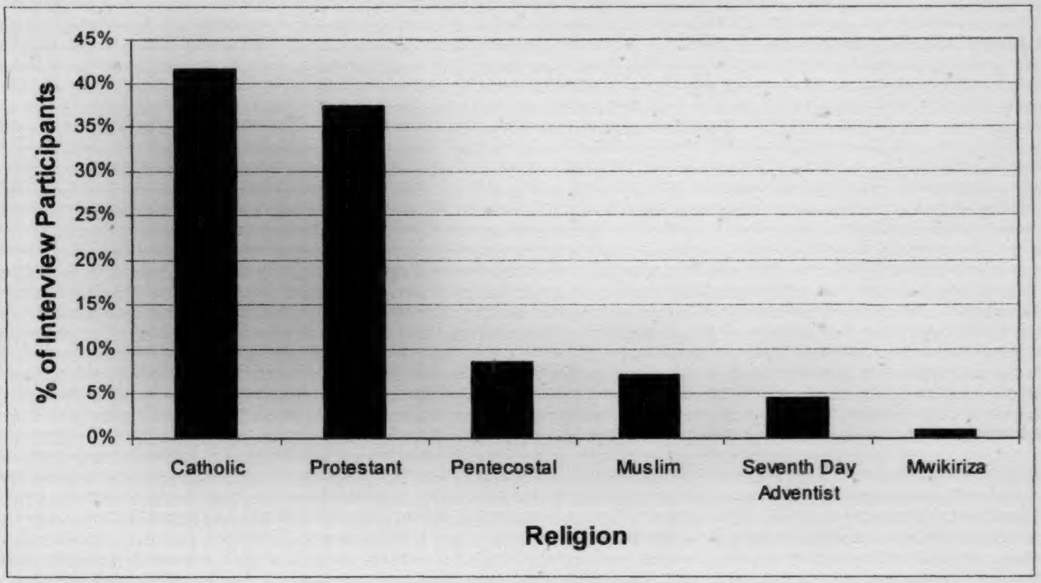


2.2.4 Religion

The interview participants belonged to a wide variety of religions (figure 2.2.4). The most popular religion was Catholicism followed by Protestantism, Pentecostal, Muslim and Seventh Day Adventist. A small number of respondents practice Mwikiriza, which translates directly as "believer". These individuals worship the prophet Bisaka and this religion exists mainly within Eastern and Central Africa. There was a significant difference (p=0.032) in participants by religion with HIV positive individuals more likely to be Catholic and HIV negative individuals were more likely to be Muslim.

The interview participants tended to attend religious services regularly. The majority of participants attended one religious service per week (77%, n=324) and 19% (n=81) of respondents attended services more frequently. Only 3.8% of respondents attended services less than once a week with 3.1% (n=13) attending 1-3 religious services per month and 0.7% (n=3) less than once a month.

Figure 2.2.4: Interview Participants by Religious Affiliation



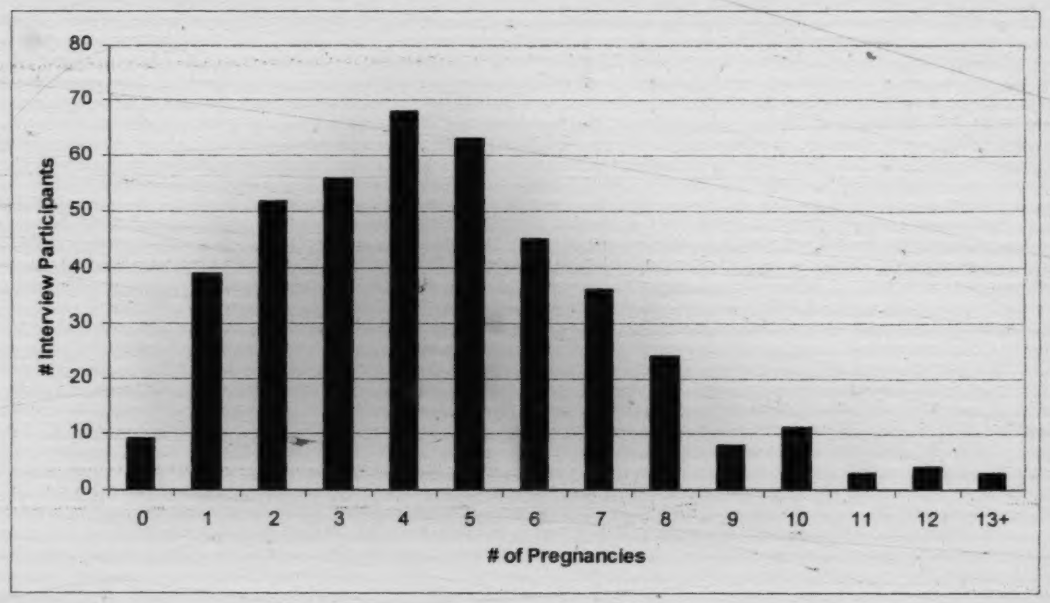
2.2.5 Ethnicity

The study area is an ethnically diverse region. Most of the research participants either belonged to the Mukiga tribe (37%, n=157) or the Mutooro tribe (36%, n=150). The study also included individuals who were of the Mukonjo (11%, n=47) and Munyankole (8.3%, n=35) tribes. The remaining interview participants (7.4%, n=31) belonged to other East African tribes.

2.2.6 Number of Children

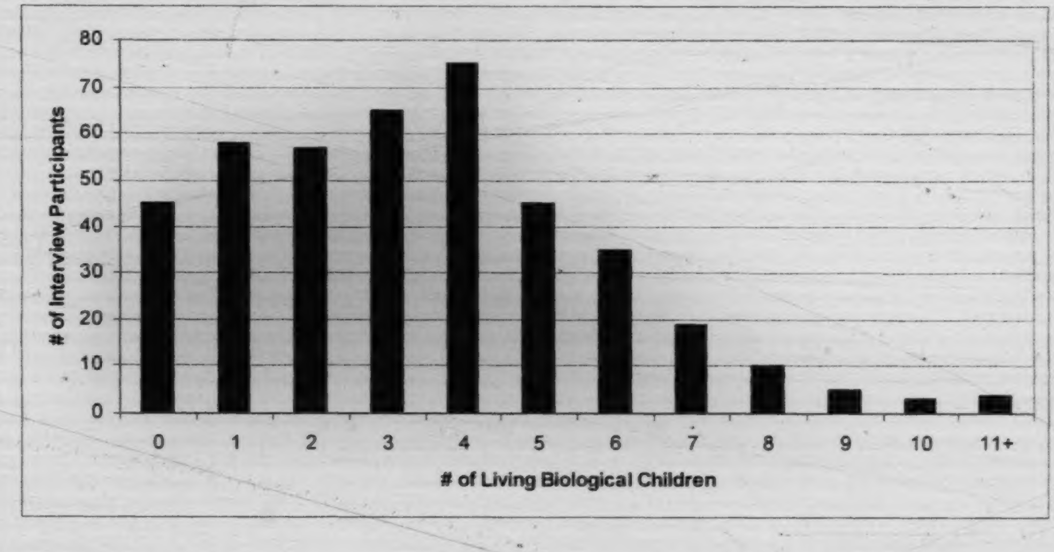
Number of children can be assessed in a variety of ways. We obtained data on number of pregnancies, living children and non-biological children. The total number of pregnancies a woman has carried or a man is responsible for are shown in figure 2.2.6a. This includes current pregnancies, miscarriages, stillbirths and children who died after birth. The number of pregnancies was significantly greater for HIV positive individuals when compared to negative individuals (p=0.0203) but not when men and women were compared (p=0.3906). The average number of pregnancies per individual was 4.6. Only 2.1% (n=9) of individuals had never been pregnant/impregnated a partner. Of the participants who were asked whether they/their partner was currently pregnant (n=365), 43% replied "yes".

Figure 2.2.6a: Interview Participants by Number of Pregnancies



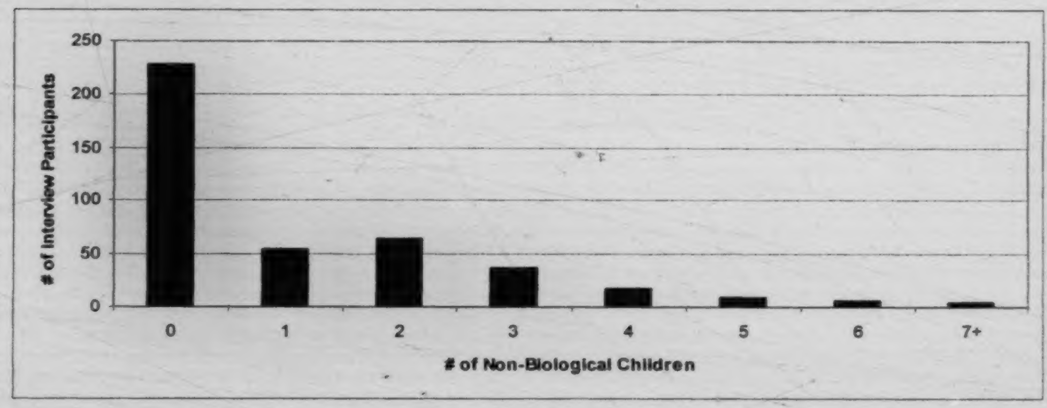
Data on the number of living biological children for the interview participants is shown in figure 2.2.6b. The average number of living biological children was 3.4. HIV positive individuals tended to have more living children than negative participants (4.0 versus 2.9, $p<0.0001$) and men had more living children than women (3.8 versus 3.2, $p=0.0226$). However, this may be due to the higher average age of HIV+ individuals and men when compared with HIV- individuals and women.

Figure 2.2.6b: Interview Participants by Number of Living Biological Children



Many research participants (46%) acted as the primary caregiver for children they had not given birth to/fathered. These often include step children or children of deceased family members. HIV positive participants were more likely to care for non-biological children than negative individuals ($p<0.001$) and men were more likely to care for non-biological children than women ($p=0.001$). As shown in figure 2.2.6c the participants tended to care for a small number of non-biological children; however there were cases when up to ten non-biological children were being looked after by an interview participant.

Figure 2.2.6c: Interview Participants by Number of Non-Biological Children

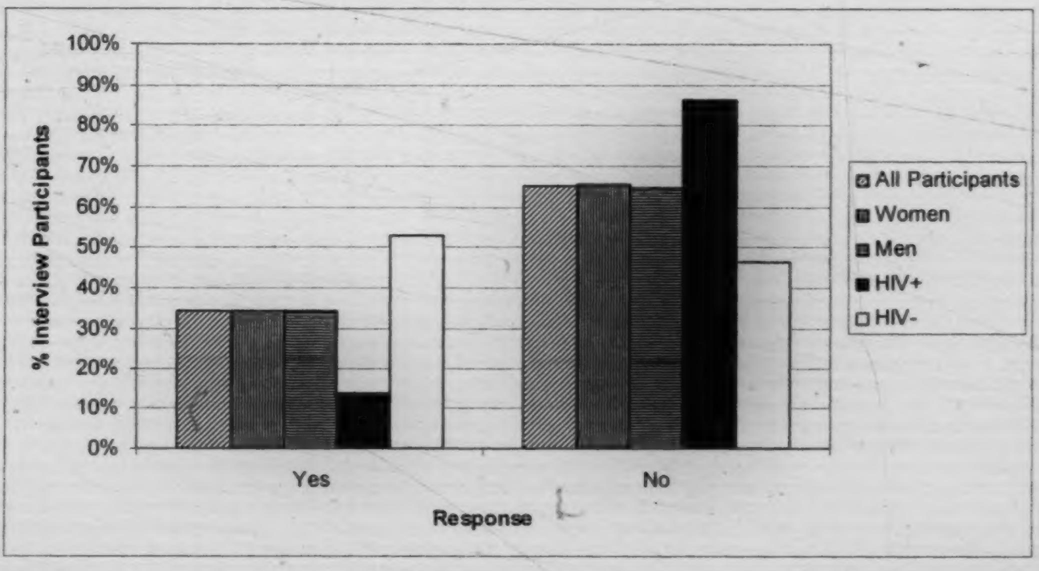


2.3 Descriptive and Univariate Analysis

2.3.1 Desire for Children

Figure 2.3.1a shows the results stratified by age and HIV status for the responses to the question "do you want to have children?" (for those who were childless) or "Do you want to have more children?" (for those who already had children). If the participant or his partner was currently pregnant the question was modified to ask whether the participant wanted more children after the child that was currently being carried was born. Overall, it was found that 34% (n=145) of research participants wanted to have (more) children while 64% (n=275) wished to stop childbearing. One respondent's response was not included in this analysis as he stated that he wished to have another child only if the child his wife was currently carrying was male. The responses to this question were almost identical when stratified by sex (p=0.963). However, when stratified by HIV status it was clear that many more HIV negative individuals wanted to continue childbearing when compared with HIV positive individuals (p<0.001). Those who had two or more living children were less likely to want to continue childbearing than those who had one or zero living children (21% versus 75%, p<0.001).

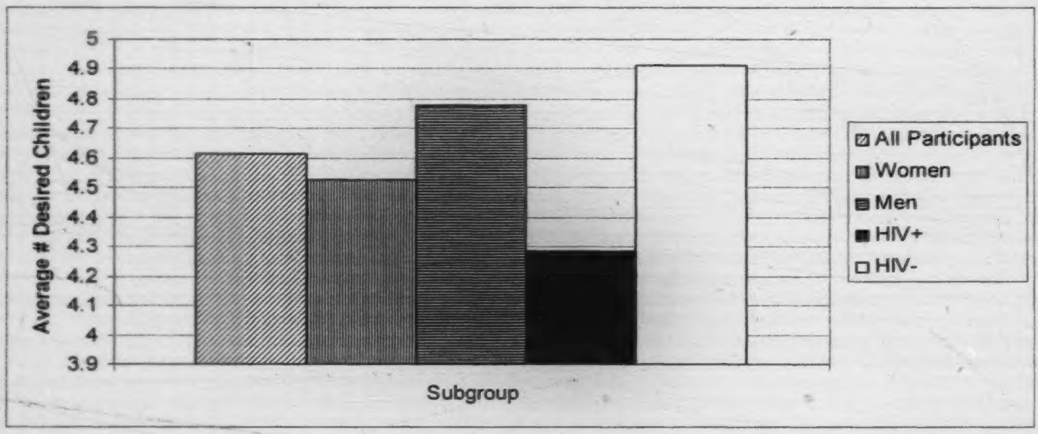
Figure 2.3.1a: Response to the question "Do you want (more) children?"



Those that wanted to continue childbearing wanted an average of 2.4 additional children (n=145). The responses to this question were once again similar between the sexes and quite different with respect to HIV status: 2.5 for women (n=92) versus 2.3 for men (n=53) and 2.6 for HIV negative (n=118) versus 1.6 for HIV positive (n=27).

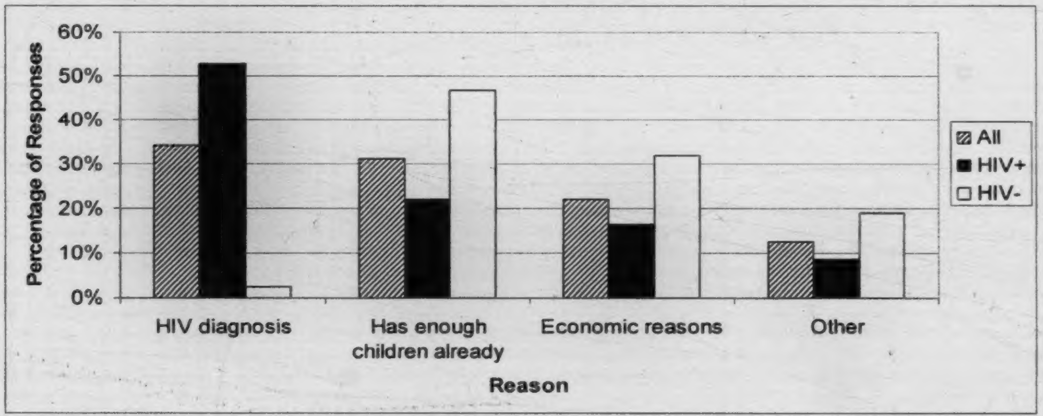
When the number of living children an individual had (including current pregnancy, if applicable) was added to the number of additional children they wanted, a value of "desired children" was obtained, shown in figure 2.3.1b. This terminology may be a bit of a misnomer for those who have already had more children than they desired but is used for convenience. It was found that the research participants desired 4.6 children on average. Men desired more children than women but this finding was not significant (p=0.2416). When examined by HIV status the findings significantly demonstrated that HIV positive individuals desired fewer children than negative individuals (p=0.0025).

Figure 2.3.1b: Average # Desired Children by Subgroup



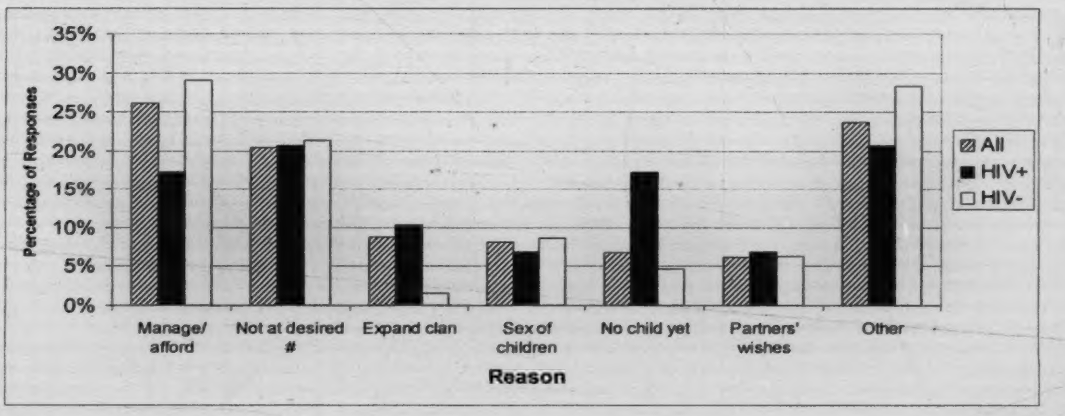
The 275 individuals who responded that they wished to stop childbearing were asked their reasons for this decision. As some respondents gave multiple answers to this question there were 344 responses that were coded into groups. The percentage of times each response was given, for all participants as well as stratified by HIV status, is shown in figure 2.3.1c. Two of the three most common reasons, having enough children already and economic concerns, were given frequently by both HIV positive and HIV negative individuals. In contrast, HIV diagnosis of themselves or their partner was given as a reason to stop childbearing predominantly by HIV positive individuals.

Figure 2.3.1c: Participants Reasons for Wanting to Stop Childbearing



The interview respondents' reasons for wishing to continue childbearing, stratified by sex, are shown in figure 2.3.1d. The 145 respondents who were asked this question gave 161 responses, as more than one response to the question was permitted. HIV positive individuals were more likely to want to continue childbearing to expand their clan or because they did not yet have any children, whereas negative participants wanted more children because they could manage and/or afford to care for them.

Figure 2.3.1d: Participants Reasons for Wanting to Continue Childbearing



2.3.2 Partner Communication Surrounding Reproductive Decisions

Respondents were asked if they had discussed either stopping childbearing or how many children they wished to have with their current partner. Of the 275 interview participants who said they wished to stop childbearing the vast majority (90%, n=248) had discussed stopping with all of their partners. In contrast, 8.4% (n=23) had not discussed it with their spouse/spouses and 0.7% (n=2) discussed it with some but not all of their spouses. For the 145 respondents who wished to continue childbearing, once again the majority (76%, n=110) had discussed the number of children they wished to have with their partner(s) whereas 23% (n=34) had not. Thus, most interviewees reported partner discussions with respect to reproductive decisions but the discussion was more likely to occur on the topic of stopping childbearing than on how many children to have. Having had either type of discussion was more common for HIV positive individuals (91%) than for HIV negative individuals (81%) and this finding was significant (p=0.002). Participants did not differ in whether or not they had had these discussions when they were compared by sex (p=0.136).

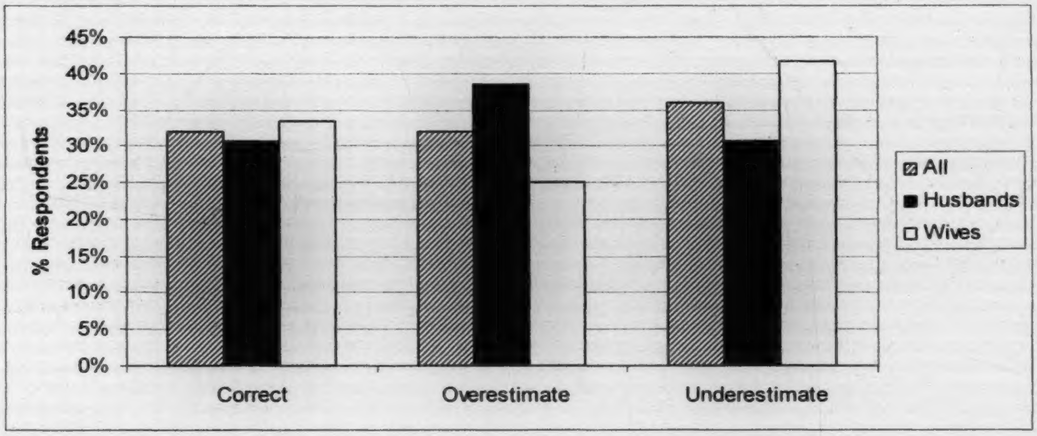
Those who said that their HIV diagnosis influenced the number of children they wanted to have were also asked if they had discussed this new desire with their partner following their diagnosis. Ninety percent (n=85) reported having had this discussion with their partner whereas ten percent (n=9) did not.

The two most common reasons for not discussing reproductive issues with the partner included that the participant had never thought about it or that the husband decides alone so there is no point in the wife providing input (each reason was given by 10 respondents). The next most common reason, given by five participants, was that they did not have time to discuss it or that the right time to discuss it had not yet arisen. Four respondents did not discuss these issues either because they thought they/their partner was barren, they just never bothered to talk about it or because they were fearful/unsure about how to bring up the subject. Three respondents did not have a discussion because they did not require their partner's input as they made these decisions alone. Eleven interviewees gave reasons for not discussing reproductive issues that did not fall into any of the above categories.

Those who wanted to have more children and said they had discussed this with their partner were asked how many more children their partner wanted. Of this group of individuals (n=111), the majority (69%, n=77) responded that their partner wanted the same number of children as they did. For those who had differing opinions on the number of children each partner wanted (21%, n=23) it was about twice as likely that the husband was perceived as wanting a greater number of children (14%, n=15) than the wife (7.2%, n=8). This question could not be evaluated for all respondents because 8.1% (n=9) were not sure how many children their partner wanted even though they claimed to have discussed with them the number of children they would have together. One point eight percent (n=2) of the respondents reported their partner believed it was "up to God to decide" how many children they had.

By pairing the responses given by both partners of a couple we were able to gain more information regarding how accurate knowledge was about partners' reproductive desires. Those who wanted more children (n=25) were asked how many children they wanted to have as well as how many their partner wanted to have in the future. When the responses of how many additional children one individual wants are compared with how many their partner thinks that they want the results show that only 32% of respondents could correctly identify how many more children their partner wanted to have (figure 2.3.2). Of the 68% of respondents who answered this question incorrectly, 32% overestimated their partners' fertility desires and 36% underestimated them. In general, men and women identified their partner's desires correctly about the same percentage of the time. Wives were more likely than husbands to underestimate their partners' desire for children.

Figure 2.3.2: Do couples know their partner's fertility desires?



By comparing couples responses we were also able to determine if both partners agreed as to whether or not a discussion surrounding reproductive decisions took place. Of the 60 couples for which this data was available 78% were in agreement with respect to whether or not a discussion had occurred regarding stopping childbearing or how many children to have together. However, the percent agreement was much higher for those who were asked if they had had a discussion about stopping childbearing (88% agreement in a sample of 41 couples) rather than those who were asked if they had discussed how many children they wished to have together (58% agreement for a sample of 19 couples).

2.3.3 Control over Reproductive Decisions

Control of reproductive decision-making was assessed by asking respondents one of the following questions: "Does whether or not you will stop childbearing depend more upon what your partner(s) want(s) or on what you want?" (for those who wanted to stop childbearing) or "Does the number of children that you will have with your partner(s) depend more upon what your partner(s) want(s) or on what you want?" (for those who wanted to continue childbearing). For both questions the majority of participants responded that they decide these issues equally with their partners, although this is slightly more common for those who wanted to stop childbearing (77%, n=211) when compared with those who wanted to continue childbearing (61%, n=88). The second most common response was that the participant has more say over these matters than their partners do (15%, n=40 for stopping childbearing and 26%, n=38 for how many children to have). Eight percent (n=22) of interview participants stated that their partner has more control of whether or not they will stop childbearing and 12% (n=17) said their partner has control over deciding how many children they will have.

When these two questions (regarding who decides about stopping childbearing and who decides the number of children to have) are grouped together the results differ significantly when stratified by HIV status (p=0.007) and are of borderline significance when stratified by sex (p=0.054). HIV positive individuals were more likely to say that each partner had equal say in reproductive decisions whereas the negative individuals were more likely to say that they decide themselves or that their partner decides for them. When stratified by sex, the results are comparable for the percentage of individuals who decide these issues equally and who decide themselves. However, the percentage of women who say that their partner has more influence on RDM (12%, n=32) is more than twice the percentage of men who responded this way (4.7%, n=7). This is also supported by the fact that 8 out of 10 individuals who said they wanted to have children to satisfy their partners' wishes were female (from the question asking why individuals wish to continue childbearing discussed earlier in section 2.3.1).

There are 59 couples for which both partners were asked the same question regarding control over reproductive decisions. Overall, there was agreement in the answers given by 64% of respondents as to who maintained control over RDM.

2.3.4 Contraceptive Behaviours

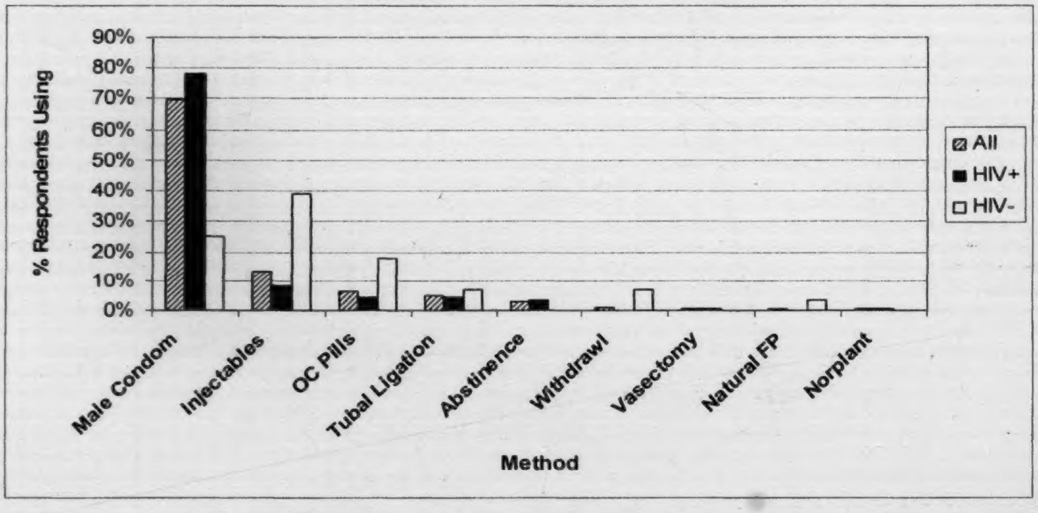
The questionnaire assessed both ever use and current use of contraception. Overall, 65% (n=274) of respondents reported using contraception at some point in their lives whereas 34% (n=144) had never used it. The percentage who had ever used contraception was higher for HIV positive individuals (86%, n=171) than HIV negative individuals (46%, n=103) and this result was statistically significant (p<0.001). There was also a statistically significant difference when contraceptive use was compared between the sexes: men were more likely to report contraceptive use than women (74% versus 61%, p=0.007) which remains even after controlling for the participants' level of educational attainment.

In total, 42% (n=176) of respondents were currently using contraception. Once again, the HIV positive participants (74%, n=148) were much more likely (p<0.001) to be current users of contraception than HIV negative participants (13%, n=28), as well men (53%, n=79) were more likely (p=0.001) to be current users than women (36%, n=97). However, many HIV positive individuals were using condoms to prevent infection/reinfection even though they are not a very reliable method of birth control. Thus, the variable "current use –effective methods" was created to include only those using methods that are greater than 95% effective with typical use (injections, OC pill, abstinence, Norplant, vasectomy, tubal ligation) and excluding less effective methods of birth control (male condom, natural family planning, withdrawal). Only 12% of respondents (n=52) were currently using effective methods of birth control. It was found that HIV positive individuals were still more likely than negative individuals to use effective methods, however the gap had narrowed (17% HIV+, 8% HIV-, p=0.005). Similarly, men were more likely than women to report use of effective methods but the difference between the sexes was less for effective methods than for all methods (17% men, 10% women, p=0.05).

Current use of contraception was also assessed for only those who were currently at risk of pregnancy. This excludes those who reported being currently pregnant and/or breastfeeding, subfecund/infecund or having infrequent sex. Sixty-nine percent (n=168) of individuals who were at risk of pregnancy (n= 242) were currently using contraception. HIV positive respondents (79%, n=143) were still much more likely to be currently using contraception than HIV negative respondents (40%, n=25) even when only those at risk of pregnancy were included in the analysis and this result was highly statistically significant (p<0.001). Men and women no longer differed in current contraceptive use when only at risk individuals were included (p=0.441). It was found that 21% (n=51) of at risk individuals were currently using effective methods of birth control. When at risk individuals using effective methods were compared by sex and HIV status there were no significant differences found between the groups. When only those who want more children were analyzed it was found that 81% of those currently at risk were using family planning (any method) but that only 22% were using a highly effective method. Thus, the unmet need for family planning services in this sample is 19%; however, 78% have a need for a more highly effective method of contraception.

Those currently using contraception were asked which methods(s) they were using (figure 2.3.4a). The most common method overall was the male condom, followed by injectables and the oral contraceptive pill. There were 8 individuals who used dual protection in the form of the male condom plus either injectables, the oral contraceptive pill or tubal ligation. Seven of these individuals were HIV positive, all of them were men, and overall these eight users of dual protection represent 4.5% of current contraceptive users. Current use method choice differed for HIV positive and negative individuals ($p<0.001$) and for men and women ($p=0.006$). HIV positive respondents tended to favour the male condom followed by injectables and dual method use. In contrast, the HIV negative respondents most commonly utilized injectables and then the male condom followed by pills. Men were more likely to report use of injectables and dual method use whereas women were more likely to report male condom use.

Figure 2.3.4a: Methods of Choice for Current Contraceptive Users



Current users of contraception were asked why they chose to use their method over the other ones. Respondents were allowed to offer multiple reasons for their decision which are summarized in figure 2.3.4b. The most commonly cited reason was to avoid infection and/or reinfection with the HIV virus followed by convenience/ease of use. Those not currently using contraception were asked their reasons that influenced this choice, which are shown in figure 2.3.4c.

Figure 2.3.4b: Reasons for Using Current Method of Contraception

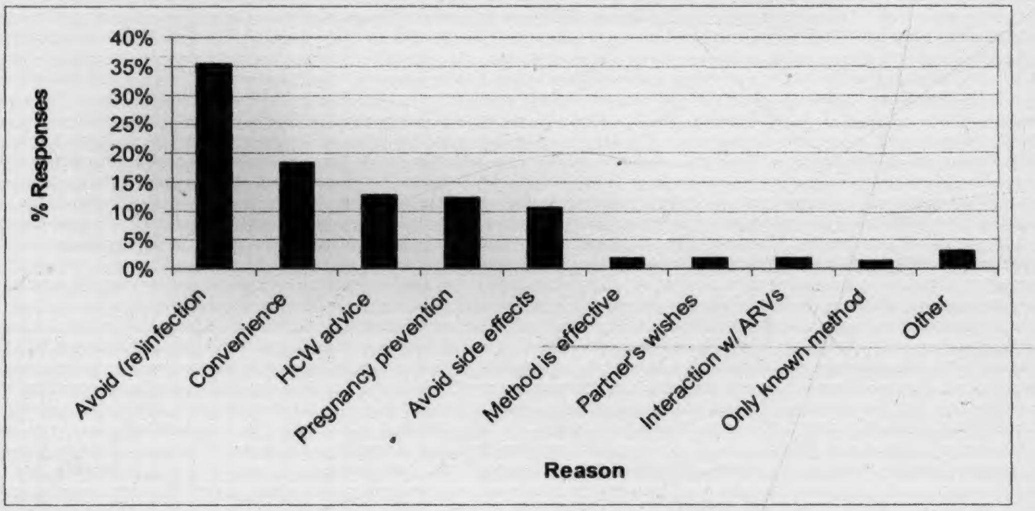
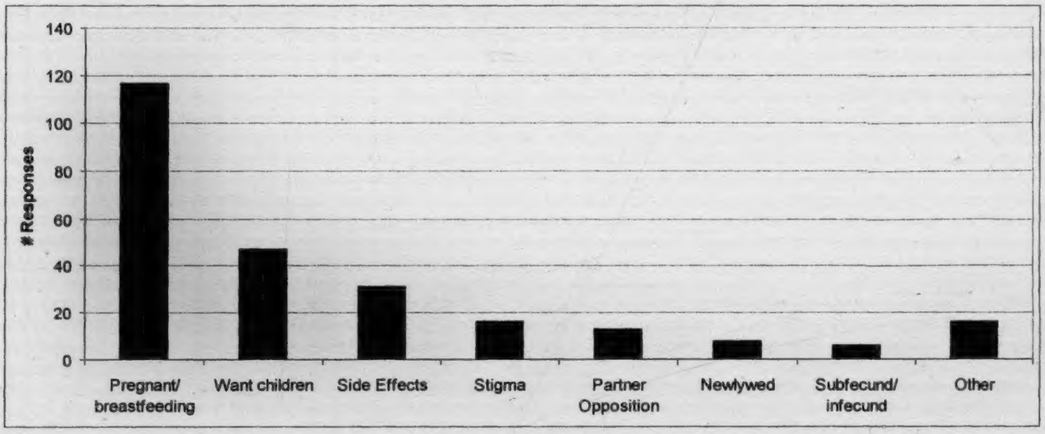


Figure 2.3.4c: Reasons for not Currently Using Contraception



To further assess the barriers that inhibit Ugandans of Kabarole region from using contraception the interview participants were asked if they had ever wanted to use contraception but not been able to. Overall, 23% (n=96) responded "yes" to this question, and there was no difference between HIV positive and negative individuals (p=0.739) or between men and women (p=0.167). The most common reason by far, which was cited by 67% (n=64) of those who had been unable to use it, was side effects. This was followed by stigma (9.5%, n=9), partner opposition (6.3%, n=6) and having conceived while using family planning in the past (5.3%, n=5). Less common reasons include forgetting to take the oral contraceptive pill (4.2%, n=4), finding family planning too expensive (2.1%, n=2) and the clinic/store being too far from the respondents' home (2.1%, n=2).

Since side effects were commonly mentioned as a reason why respondents were unable to use contraception questions were added to assess which symptoms were causing the most problems for the respondents. By far the most commonly cited symptom was continuous bleeding and/or over bleeding during monthly periods, which was mentioned 47% (n=35) of the time. The next most common side effects were weakness (15%, n=11) and dizziness (9.5%, n=7). High blood pressure/fast heartbeat, amenorrhea and weight loss/gain were each mentioned 5.4% (n=4) of the time.

Three women, representing 3.1% of all females who were currently using contraception, are doing so without their husband's knowledge. Two of them are HIV positive and the other is negative but fears she may actually be infected but in the window period because her husband is positive. All three of these respondents were using contraception covertly because their husbands wanted to have children but they did not. One elaborated that she was worried her partner would force her to have children even though she did not want to because she was HIV positive.

2.3.5 HIV/AIDS Characteristics

As stated previously, 47% (n=199) of the interview participants were HIV positive and 53% (n=222) were negative. Further analysis shows that 52% (n=222) of marriages were concordant, 13% (n=55) discordant and 36% (n=153) were indeterminable because the interviewee was not aware of their partners' serostatus. Note that the number of couples is greater than the number of participants because some individuals had more than one spouse and also that partner status was reported by the participant and was not confirmed by medical records or testing.

The 153 individuals who were not aware of their partners' serostatus were in this position either because their partner had not tested or because their partner had not revealed their test results to them. All participants who did not test for HIV on the same day as they were interviewed were asked if they revealed their test results to their spouse(s). This group included 246 of respondents who were either HIV positive or HIV negative men since the HIV negative women were interviewed post-test at the health centre. Of these individuals, 97% (n=239) reported revealing their test results to their partner, 0.8% (n=2) told some of their spouses but not all of them and 2% (n=5) did not disclose their serostatus to their partner(s). Their reasons for withholding this information included poor communication in all aspects of the relationship, the partner refusing to test, fear of being beaten and accused of infecting her partner and the partner being physically absent (in two cases). One of the men who told some but not all of his partners did so because one of his wives refused to test with him and the other did so because he only considers one of his spouses to be his "real wife".

The participants who were interviewed directly after receiving their test results (n=175) were asked if they told their partners that they were going to get tested for HIV that day. Overall, 84% (n=147) of respondents did inform their partner that they were coming for testing, 16% (n=28) did not. Of the 28 individuals who did not inform their partners, nine did so because they did not intend to test for HIV that day but decided to do so after they had come to the clinic and/or trading centre for other reasons. As well, ten participants did not tell their partners because they were physically absent: either out of town, not home or in prison.

All respondents were asked two questions to assess their experience with AIDS-related death. These questions are necessary to determine if experience of AIDS-related death, either in the family or in children in the community, is associated with a desire to reduce or stop childbearing upon receipt of an HIV diagnosis. The first question asks if any of the participant's family members have died of AIDS. The results show that overall 61% (n=256) of respondents have lost a family member to AIDS. The percentage of those who have experienced AIDS death in the family was higher for those who were HIV positive (72%, n=144) than for those who were HIV negative (51%, n=112) which is a statistically significant finding ($p<0.001$). The results did not differ significantly when stratified by sex ($p=0.263$).

The second question specifically addresses experience with AIDS death due to MTCT by asking participants if they knew any child under age 10 who had died of AIDS. In total, 25% (n=105) of individuals knew a child who had died of AIDS (figure 2.3.5b). Once again, the percentage was higher for the HIV positive respondents (31%, n=61) than for the HIV negative ones (20%, n=44) and these results were significant ($p=0.008$). There was no difference when the results were compared by sex ($p=0.149$).

Of the participants who were HIV positive, 65% (n=130) reported having experienced AIDS-related symptoms or illness and 61% (n=122) were receiving ART. For both of these questions the answers are similar when men and women are compared ($p=0.603$, $p=0.257$).

2.3.6 Effect of HIV/AIDS on Reproductive Decision-Making

Many interview questions assessed the impact an HIV diagnosis had on reproductive decisions. Fourteen percent of HIV positive individuals wanted to have more children versus 53% of HIV negative individuals ($p<0.001$). Number of living children greatly influenced fertility desires for HIV positive individuals: only 8% of those with two or more children wished to have additional children versus 42% of people with less than two children ($p<0.001$). Wanting to stop childbearing was more common for HIV positive participants when compared to HIV negative participants of the same parity.

Sixty-seven percent of HIV positive individuals who wished to stop childbearing mentioned their HIV status as one of the reasons for this decision. Thirty-three percent (n=65) of HIV positive respondents reported that they would have had more children if their test result had been negative instead of positive. Each of these individuals on average would have had an additional 2.3 children. Men tended to want more children than women (2.8 versus 1.8, p=0.0088) if they were diagnosed negative instead of positive.

HIV positive respondents were asked directly if their diagnosis caused them to change the number of children they wanted to have and why. HIV negative respondents were asked a hypothetical question as to whether or not their fertility desires would change if their test result had been positive rather than negative. Fifty-five percent (n=233) of individuals stated that a diagnosis did/would change their fertility desires while 6% (n=25) said that it would not and 39% (n=162) stated that it did/would not influence their fertility desires because they had already ceased childbearing for other reasons. The results were not significantly different when compared by HIV status (p=0.223) but were when compared by sex (p=0.010). Men were more likely to say that a diagnosis did/would not impact their reproductive desires than women (11% versus 3%).

Those who responded that a HIV diagnosis did/would change the number of children they wanted to have were then queried on what the effect was/would be. The vast majority stated that an HIV diagnosis did/would cause them to stop childbearing (85% HIV positive, 84% HIV negative). The next most common response was that they would have fewer children (14% HIV positive, 16% HIV negative). Only one HIV positive respondent stated that her diagnosis made her desire more children. The results did not differ by HIV status or sex.

Those who said they would have more or less children rather than stopping childbearing altogether were asked questions about the timing with which they would have their future children. Seventy-six percent (n=29) of participants said they would change the timing with which they had their future children as a result of their HIV diagnosis. They were divided on whether they would like to have their children at an older or a younger age. Fifty-five percent of individuals said they would wait until they were older while the other 45% wished to have their children at a younger age. Participants were asked their reasons behind this decision. Of the 16 participants who said that they wanted to wait until they were older, 10 said that they wanted to wait until the mother gained strength before deciding if she should become pregnant. Two respondents wanted to wait for the side effects of the ARVs to diminish before becoming pregnant and two others wanted to wait due to the advice given to them by health workers. One respondent replied that they wanted to wait so that they could space their children and the last one wanted to first plan for their children before having more. The reasons for having children at a younger age included being able to produce them (n=5) or being able to raise or care for them (n=5) before dying. Three respondents wanted to have children at a young age because they were now strong and feared they would not be in the future.

There were fifteen HIV positive respondents who had become pregnant (or their wife, who was also positive had become pregnant) following their diagnosis. Since sometimes both partners of a couple were interviewed this represents a total of 13 pregnancies. Seven of these pregnancies were in women recruited from the Bigodi site, three were from Rwimi and three were from Kibiito. Only one of these 13 pregnancies was planned. Eight of the participants who unintentionally became pregnant following their diagnosis expressed that they had wanted to use contraception and not been able to at some point in their lives. Side effects were the most commonly mentioned reason for not being able to use contraception by these participants (mentioned by six individuals).

All respondents were then asked if they thought it was okay for women who had been diagnosed with HIV to become pregnant. They were also asked if it was okay for a man to make his wife pregnant if he knows she is HIV positive. One hundred and twenty-five participants were asked this question before it was split into two questions which addressed whether or not the husband was HIV positive or negative because the research participants desired this information before responding to the question. Therefore, 295 participants were asked the more specific questions as to whether it was okay for an HIV positive or HIV negative man to make his wife pregnant if he knows she is HIV positive. Overall, 7% (n=29) of interviewees responded affirmatively to one or more of these questions. No differences were found in any of these questions when the responses were compared by sex or HIV status. The percentage of participants who responded affirmatively to each of these questions is reported in Table 2.3.6.

Table 2.3.6: Responses to Attitude Questions – Is it okay for HIV positive couples to become pregnant under certain conditions?

	% responding yes:
Any question	7.0%
Positive woman becoming pregnant	5.9%
Man making positive woman pregnant	5.6%
Positive man making positive woman pregnant	4.1%
Negative man making positive woman pregnant	0.3%

The reasons given for the responses to these questions were combined and are reported in figure 2.3.6a (affirmative responses) and figure 2.3.6b (negative responses).

Figure 2.3.6a: Reasons given for why couples where the wife is HIV positive can still become pregnant

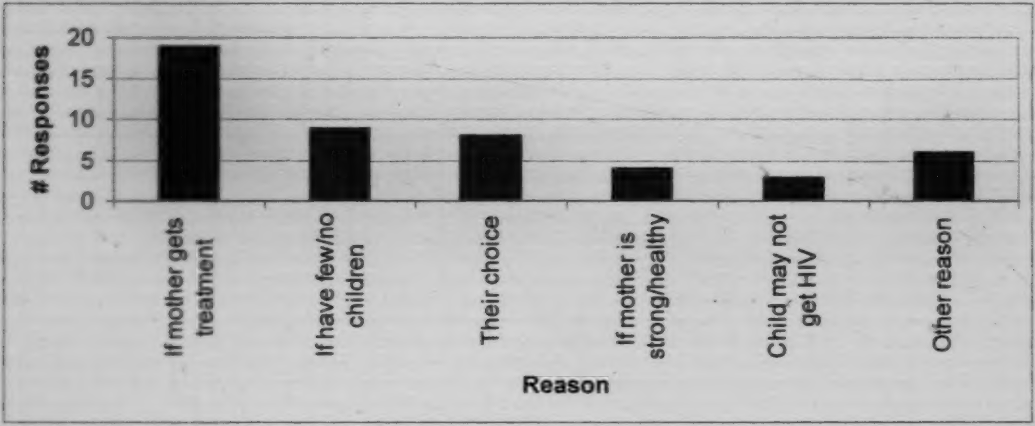
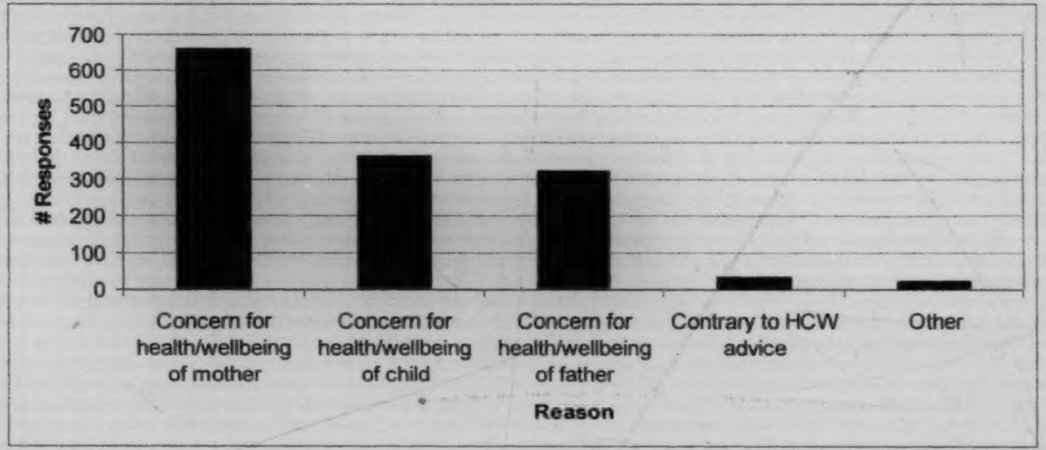


Figure 2.3.6b: Reasons given for why couples where the wife is HIV positive should not become pregnant



2.3.7 Knowledge Regarding Mother to Child Transmission of HIV

The interview participants were asked questions to assess their knowledge regarding mother to child transmission of HIV since this may be a factor which influences reproductive decisions within the context of HIV/AIDS. Overall, 97% (n=394) of respondents believed that HIV could be transmitted from mother to child during pregnancy and/or delivery. The responses to this question were similar when broken down into subgroups by HIV status (p=0.453). When compared by sex 98% of women and 95% of men said that transmission could occur (p=0.090).

In order to assess the respondent's knowledge of how ARVs influence mother to child transmission the participants who said that mother to child transmission during pregnancy and/or childbirth was possible were then asked whether this could occur if the mother was not on ART or if she was on ART. Many respondents said that it depended upon whether the woman delivered her baby in the village or the health centre. Thus, after 74 respondents had been interviewed these questions were altered to assess whether or not the participant felt that HIV could be transmitted from mother to child if she was not on ART and gave birth in either the village or the hospital or if she was on ART and gave birth in either the village or the hospital. The results of these questions are summarized in table 2.3.7a. The vast majority of participants thought that

MTCT of HIV could occur if the mother was not on ART (96%), especially if it was specified that the mother gave birth in the village (100%). However, this percentage dropped dramatically to 48% if the mother gave birth in a hospital or health centre. Only 44% of participants thought that MTCT was possible if the mother was on ART, versus 96% if the mother was not on ART. Once again, many more participants thought it was possible to transmit the virus if the mother gave birth in the village (67%) rather than the hospital/health centre (12%) even if they were all receiving ART. Note that "don't know" responses have been omitted from these calculations and that the percentage of "don't know" responses was much higher for the questions involving ARV treatment, suggesting that participants lack information regarding how ART influences MTCT (Table 2.3.7a).

Table 2.3.7a: Responses to questions about whether or not mother to child transmission of HIV is possible under different birth delivery and anti-retroviral treatment conditions

	Think MTCT possible	Don't know if MTCT possible
If mother not on anti-retroviral treatment	96%	1%
If mother on anti-retroviral treatment	44%	2%
If mother not on anti-retroviral treatment and gives birth in village	100%	0.2%
If mother not on anti-retroviral treatment and gives birth in hospital	48%	1%
If mother on anti-retroviral treatment and gives birth in village	67%	6%
If mother on anti-retroviral treatment and gives birth in hospital	12%	5%

The variable "MTCT risk understanding" was created to determine if the participants understood that the risk of MTCT was not absolute and that sometimes an HIV positive woman would produce an infected child whereas other times the child could be infected. Each question about whether MTCT could occur under different conditions was partnered with a question which asked "if there were ten HIV positive pregnant women in each of these situations, how many would transmit HIV to their child?" (Table 2.3.7b). Overall it was found that 60% of participants gave an answer that was not 0 or 10 to at least one of these questions. Thus, 60% of respondents demonstrated that they understood that the risk of MTCT is not absolute. There was no difference in risk understanding between positive and negative individuals or between men and women.

Table 2.3.7b: Responses to questions about how many children would be infected if ten HIV positive mothers gave birth under different conditions

	Average # (±SD) of children infected if 10 HIV+ women pregnant	Don't know how many would be infected
If mother not on anti-retroviral treatment	6.5 ± 2.9	2%
If mother on anti-retroviral treatment	2.1 ± 3.1	0.5%
If mother not on anti-retroviral treatment and gives birth in village	8.9 ± 1.7	7%
If mother not on anti-retroviral treatment and gives birth in hospital	2.9 ± 3.7	3%
If mother on anti-retroviral treatment and gives birth in village	4.9 ± 4.2	5%
If mother on anti-retroviral treatment and gives birth in hospital	0.5 ± 1.7	1%

As well, the variable "ARV understanding" was created to determine if participants understood that being on ARVs reduced the chances of MTCT. It was found that 41% of respondents consistently responded that ART of the mother reduced the chance of MTCT. Not surprisingly, HIV positive respondents had a greater understanding of the influence of ART on MTCT, however this finding was not significant at the 5% significance level (p=0.084).

The variable "MTCT understanding" was created to see how participants faired overall with respect to their knowledge of MTCT. Participants were given one point if they answered any of the questions regarding MTCT in the absence of ARVs in the correct range and one point if they answered any of the questions regarding MTCT in the presence of ARVs in the correct range. The correct range was defined as 1-5 children becoming HIV infected if the mother was not on ARVs and 1-3 children becoming infected if the mother was on ARVs (regardless of birth location). The range for those on treatment would include the correct value for those on HAART as well as for those receiving Nevirapine. Participants were categorized as having "high" MTCT understanding if they attained one or more points and "low" understanding if they did not get any points. Overall, 27% (n=114) had high MTCT understanding and this value did not differ by HIV status. However, men tended to have higher MTCT understanding than women (34% versus 23%, p=0.011).

2.3.8 Health Services

Of the 13 pregnancies that occurred in HIV positive women following their diagnosis, eight received PMTCT. Of the five that did not, two miscarried early in their pregnancy. Those who received PMTCT services all reported disclosing their HIV status to every health worker they came into contact with during their pregnancy and/or delivery. In order to assess whether or not these women were discriminated due to their serostatus they were asked if they were treated differently by the health workers than the women who had not tested HIV positive. Five respondents said they were not treated differently and the three who were treated differently said that they were given extra care, additional counseling and/or special treatment (such as Nevirapine and food). None of these respondents reported discrimination or negative treatment from the clinic staff.

All participants were asked if they were counseled regarding MTCT and family planning during their VCT session. Seventy-seven percent (n=321) of respondents reported that MTCT was discussed during their VCT session. It was more likely that HIV positive (83%) individuals were counseled on this matter when compared to HIV negative (72%) individuals (p=0.004). Men were counseled on MTCT more than women but this finding was not significant (82% versus 75%, p=0.097). Eighty-two percent (n=340) of respondents reported that family planning was discussed during their VCT session. Once again, more HIV positive individuals reported being counseled on this topic than HIV negative individuals (93% versus 75%, p<0.001). This time there was a significant difference between men and women (p=0.001): men were more likely to report FP discussion during their VCT session (90%) than women (77%). As the study was being conducted we became curious as to whether the family planning counseling only involved condoms, which reduce HIV transmission as well as prevent pregnancy, or also on other methods of family planning that are not useful in preventing HIV transmission. For those who responded that family planning was discussed after the question was broken down about one third (n=99) said that condoms were the only method discussed whereas over two thirds (n=207) said that condoms as well as other contraceptive methods were discussed.

2.4 Univariate and Multivariate Analysis

Logistic regression analysis was performed to determine if the odds of wanting to stop childbearing were different for HIV positive and negative individuals. Univariate and multivariate data are shown in Table 2.4. Multivariate data is shown only for those variables included in the final model (those that were excluded remain blank). This parsimonious model shows that the odds of wanting to stop childbearing are 12.3 times greater for HIV positive individuals than for HIV negative individuals (95% CI: 2.7-54.8, p=0.001). Positive HIV status, greater number of living children and attitude that it is not okay for HIV positive people to become pregnant were significant predictors of desire to stop childbearing. The following variables were not significant predictors but were kept in the model because they are deemed in the literature to be important to the outcome of interest: age, sex, dwelling quality (a measure of socioeconomic status), education, religion, tribe, partners' HIV status, experience of AIDS symptoms, ARV treatment.

The results from the multivariate analysis reveal changes in the direction and/or strength of the relationships for many of the variables when compared to with the univariate analysis. This is due to confounding by other variables. For example, sex was not found to be associated with the desire to stop childbearing in the univariate analysis but the multivariate analysis showed that women were much more likely than men to want to stop childbearing (although this result was not statistically significant at the alpha level of 0.05). This is due to confounding by the age and HIV serostatus variable (and potentially by other variables as well). Similarly, the tribe, partner serostatus, AIDS symptoms and AIDS treatment variables were all confounded by HIV serostatus. Thus, it is important to keep many of the non-significant variables in the model as they act as confounders.

In order to determine if the differences in recruitment sites were biasing our results, the model was also run using only the data from the participants recruited from the Rwimi Health Centre (n=325). These participants included all of the HIV negative recruits as well as about half of the HIV positive respondents who participated in the study (52% of HIV positive individuals were recruited from Rwimi, 35% from Kibiito and 13% from Bigodi). The results of this Rwimi-only model were very similar those of the original model (OR=11.06, 95% CI: 2.04-59.99, p=0.005), proving that the use of three recruitment sites for the HIV positive participants did not bias findings.

Table 2.4: Univariate and Multivariate Values for Logistic Regression Model with Desire to Stop Childbearing as the Dependent Variable

	Univariate Analysis		Multivariate Analysis	
Variable	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Recruitment Site				
Rwimi (n=325)	1.00 (reference)			
Bigodi (n=26)	5.76 (1.70-19.57)	0.005		
Kibiito (n=70)	16.78 (5.17-54.47)	<0.001		
Age (n=421)	1.23 (1.18-1.29)	<0.001	1.08 (0.99-1.18)	0.071
Sex				
Female (n=270)	1.00 (reference)		1.00 (reference)	
Male (n=151)	0.99 (0.65-1.5)	0.963	0.41 (0.16-1.07)	0.068
Marital Status				
Married (n=254)	1.00 (reference)			
Cohabiting (n=164)	1.39 (0.91-2.11)	0.127		
# Spouses				
One (n=406)	1.00 (reference)			
Multiple (n=15)	0.59 (0.21-1.66)	0.319		
Occupation				
Farmer/peasant (n=316)	1.00 (reference)			
Businessperson (n=41)	1.35 (0.66-2.75)	0.406		
Other (n=64)	1.23 (0.69-2.19)	0.480		
Dwelling Quality				
Low (n=50)	1.00 (reference)		1.00 (reference)	
Medium (n=319)	2.82 (1.53-5.16)	0.001	1.54 (0.43- 5.54)	0.509
High (n=52)	2.40 (1.08-5.34)	0.031	2.44 (0.38-12.17)	0.330
Ownership				
2 or less (n=107)	1.00 (reference)			
3 (n=91)	0.68 (0.38-1.23)	0.206		
4 (n=120)	0.85 (0.49-1.50)	0.580		
5 (n=103)	0.72 (0.40-1.28)	0.261		
Education				
None (n=70)	1.00 (reference)		1.00 (reference)	
Lower Primary (n=131)	0.74 (0.39-1.40)	0.349	0.48 (0.13- 1.74)	0.264
Upper Primary (n=164)	0.56 (0.30-1.04)	0.065	0.91 (0.26- 3.23)	0.884
Lower Second. + (n=56)	0.85 (0.39-1.86)	0.692	1.96 (0.34-11.20)	0.450
Religion				
Catholic (n=175)	1.00 (reference)		1.00 (reference)	
Protestant (n=157)	0.75 (0.48-1.19)	0.222	0.84 (0.32-2.18)	0.718
Muslim (n=30)	1.07 (0.46-2.49)	0.876	1.16 (0.21-6.27)	0.864
Other (n=59)	0.77 (0.42-1.43)	0.408	0.70 (0.20-2.46)	0.574

Religiosity				
> once a week (n=81)	1.00 (reference)			
Once a week (n=324)	0.92 (0.55-1.53)	0.741		
< once a week (n=16)	1.50 (0.44-5.09)	0.516		
Tribe				
Mutooro (n=150)	1.00 (reference)		1.00 (reference)	
Mukiga (n=157)	0.21 (0.12-0.37)	<0.001	0.48 (0.16-1.41)	0.181
Mukonjo (n=47)	0.16 (0.08-0.34)	<0.001	0.27 (0.05-1.48)	0.131
Other (n=66)	0.22 (0.11-0.43)	<0.001	0.43 (0.12-1.50)	0.184
Pregnant				
Yes (n=156)	1.00 (reference)			
No (n=206)	3.42 (2.18-5.35)	<0.001		
Experienced Death of a Child?				
Yes (n=172)	1.00 (reference)			
No (n=249)	0.83 (0.55-1.25)	0.361		
# Living children (n=421)	1.95 (1.69-2.26)	<0.001	2.04 (1.50-2.77)	<0.001
# Non-bio children				
0 (n=228)	1.00 (reference)			
1 (n=54)	2.01 (1.05-3.85)	0.035		
2 (n=64)	3.03 (1.56-5.89)	0.001		
3 or more (n=75)	2.45 (1.36-4.42)	0.003		
HIV Status				
Negative (n=222)	1.00 (reference)		1.00 (reference)	
Positive (n=199)	7.30 (4.50-11.84)	<0.001	12.27 (2.75-54.79)	0.001
Partner HIV Status				
Negative (n=222)	1.00 (reference)		1.00 (reference)	
Positive (n=199)	5.90 (3.16-10.99)	<0.001	1.06 (0.38-2.99)	0.913
Status disclosure to partner				
Yes (n=239)	1.00 (reference)			
No or not with all partners (n=7)	0.60 (0.11-3.17)	0.544		
AIDS Death in Family				
Yes (n=256)	1.00 (reference)			
No (n=163)	0.53 (0.35-0.80)	0.002		
AIDS Death of Child				
Yes (n=105)	1.00 (reference)			
No (n=311)	0.60 (0.37-0.98)	0.041		
AIDS symptoms				
Yes (n=130)	1.00 (reference)		1.00 (reference)	
No (n=291)	0.19 (0.11-0.33)	<0.001	1.46 (0.29-7.48)	0.647
ARV treatment				
Yes (n=122)	1.00 (reference)		1.00 (reference)	
No (n=299)	0.15 (0.08-0.28)	<0.001	1.26 (0.28-5.76)	0.762
MTCT possible				
Yes (n=394)	1.00 (reference)			
No (n=14)	0.93 (0.31-2.83)	0.900		
MTCT Understanding				
Low (n=307)	1.00 (reference)			
High (n=114)	1.08 (0.68-1.69)	0.754		
MTCT Risk Understanding				
Yes (n=235)	1.00 (reference)			
No (n=159)	0.79 (0.52-1.20)	0.266		
MTCT ARV Understanding				
Yes (n=161)	1.00 (reference)			
No (n=233)	0.96 (0.63-1.47)	0.846		

Attitude – ok pos people pregnant						
Yes (n=29)	1.00	(reference)		1.00	(reference)	
No (n=392)	4.00	(1.81-8.85)	0.001	9.24	(1.69-50.44)	0.010
MTCT discussed during VCT?						
Yes (n=321)	1.00	(reference)				
No (n=95)	0.64	(0.40-1.02)	0.061			
FP discussed during VCT?						
Yes (n=340)	1.00	(reference)				
No (n=76)	0.31	(0.18-0.51)	<0.001			

Chapter 3: Results – Focus Group Discussions

Six focus group discussions and one in-depth interview were analyzed using thematic analysis. This entailed organizing the data into categories and then extrapolating overarching themes.

3.1 Categories

The categories, subcategories and sub-subcategories from the qualitative data are listed below and described in the sections that follow:

Childbearing in General

- Factors that Promote Childbearing
    - expectation in marriage
    - lineage/clan
    - cultural beliefs
    - searching for specific sex
    - other
- Factors that Limit Childbearing and/or Family Size
    - economic concerns
    - child mortality
    - infertility
- Cultural Norms
    - ideal family size
    - male/female differences in fertility desires
    - ideal family composition
    - fostering
    - delivery practices
    - responsibilities
- Reproductive Decision-Making Process
    - discussion
    - planning
    - control over reproductive decisions

Family Planning

- Norms
    - norms of use
    - decision to use
    - methods
- Barriers
    - side effects
    - stigma/misconceptions
    - knowledge/counseling
    - partner opposition
    - cost
    - other

HIV/AIDS in General
  Testing
  Treatment
Childbearing and HIV/AIDS
  Influence of HIV diagnosis on reproductive decision-making
  Challenges/concerns
    - wellbeing of parents
    - wellbeing of child
    - lack of concern
  Interventions to reduce mother-to-child transmission
    - family planning
    - prevention of mother-to-child transmission services
    - child spacing
    - drugs
    - delivery location
    - breast milk alternatives
  Stigma/discrimination
    - Health care workers
    - Community

3.1.1 Childbearing in General

In order to understand why HIV positive individuals might wish to have children, it was important to consider the factors that influence childbearing in general, excluding HIV/AIDS related factors. These factors are discussed below.

3.1.1.1 Factors that promote childbearing

Expectation in marriage

Having children is a very important part of Ugandan culture. Marriage is seen not to be a union of two individuals, but rather a situation where the woman joins the man's family and produces children for his clan. Thus, having children is an expectation of marriage. Children are seen as a necessary component of a strong marriage; as the glue that holds the husband and wife together during difficult times.

If a couple is married for some time but does not have children, it is assumed that one of them is infertile. While a few respondents felt that couples could stay together without children if one of them was barren, the majority felt it acceptable to seek children from outside the marriage should this situation arise. The consensus was that the man should try to have a child with a woman other than his wife. Should his efforts succeed, he would marry this woman and have multiple wives. Should his efforts fail, however, his revealed infertility would grant his wife permission to have children with other men. The following quotes illustrate the participant's feelings on this situation:

> *(Negative man): Me I think the two of us have got a problem so what I do I will go and have a relationship outside to find out if I am the one with a problem and if it is my wife then I marry another one and they become two.*
>
> *(Negative man): I would think that one of those people doesn't function – either the man or the woman. But the advice I would give to such people is – one of them can try somewhere else and then they can know who has the problem.*
> *(Interviewer): Now would you allow me – the woman to try somewhere else?*
> *(Negative man): No. [Laughter]. No -- it is the man to try somewhere else [Laughter].*
>
> *(Positive woman): If I am the one who is barren, I would not stop my husband from having children outside marriage. (Positive woman): And I expect him to also let me have children if he is the one with a problem [Laughter].*

Not surprisingly, many women fear that their husband will not be faithful to the marriage if they do not have his desired number of children. Divorce was also mentioned as a more serious consequence of not having children. Women noted these fears and men offered justification for their concerns:

> *(Positive woman): Me I am saying if you don't give birth in that home you are married the man will stop loving you -- he will start saying I rather marry someone else who will bear children for me.*
>
> *(Positive woman): I also say it is a woman who wants children mostly – because like in our village there is a man, he has three children outside marriage and the wife at home has three but because the woman failed to have more children, the man went out.*
>
> *(Negative man): You see I the man I am the household head, am the one who looks for the money, I know how much money I have so I will tell the woman to continue giving birth according to my income and if she refuses I divorce her and marry another woman.*
>
> *(Health worker): And also another challenge that we get from these ladies is that because they believe that the women – men go out for other women because they are not delivering. So they decide to keep on delivering not because they want but as a measure to stop men from getting other women.*

Lineage/clan

It was quite common for the respondents to desire children in order to leave a representative on earth after their death. There was both a desire to see themselves through their children as well as to leave a legacy. Although mentioned by participants of each sex, it was more common for men to report these desires:

> *(Negative man): Me I see the reason as to why we have children is to keep our names so that after you have died people can always say this is Mr. So and So's child or this daughter/son resembles the late father, not to die completely without leaving anything in this world.*
>
> *(Negative man): The reason why I want to have children is for example when my father died his name didn't die because he had left children, so I also want that by the time I have left this earth, I will not be forgotten – people will always say "this is XXX's child".*

The clan is a term used to describe the husband's family. With marriage, the wife and any children she produces immediately become part of the husband's clan. Although one respondent noted that the idea of having many children to increase the size of the clan is somewhat outdated, many respondents still reported wanting children for this reason:

> *(Positive man): It is the man who mostly forces the woman that they should have children because he wants to expand his family and clan.*
>
> *(Negative man): The reason we give birth is that we want to expand our clans and know ourselves as people of the same clan and then another thing is after you have died then your property is for your children because they will also give birth, and the most important thing they will name my grandchild after me, so they keep on remembering that I also once lived.*

As indicated in the quotations above, having children offers a means of keeping the father's land and other possessions within the clan, upon his death. Ugandans believe in the importance of bearing enough children to fully occupy these possessions such that they are not taken by members of other clans:

> *(Positive woman): Me I have a man who has a lot of property - I produced and others died now I only have four and the property is there so I have to give birth to six. (Interviewer): So they shouldn't take your children's property – [Laugh]. (Positive woman): Yes.*

> *(Negative man): The reason why we give birth is that – after one has died then that person's property is taken by the children, not to be taken by other people who even are not of your clan – that is why we want to have children.*

Cultural Beliefs

There are other cultural beliefs that dictate that Ugandans should have children. One of such beliefs is the idea that couples require at least two children: one to bury the mother and another to bury the father. With no child to bury a parent, he/she might be cursed and not given a proper burial. This is further explained by one respondent:

> *(Positive man): You know – you see, people in our culture we believe that when you don't have children people won't care about burying you – people will say "what will the children say if we don't bury this person decently".*

Searching for specific sex

Many respondents reported having more children than initially desired in their attempts to obtain children of a specific sex:

> *(Positive woman): After producing the sex that you have not been producing – maybe a girl, the man will say now that you have produced a girl, we can stop – and you stop.*
>
> *(Positive woman who gave birth): ...the problem is having maybe many girls or boys first, if it was like if you have a girl first the boy follows or if it's the boy first then the girl follows – people would not have many children.*

Not having children of a specific sex can cause problems in marriage: one female respondent said that she feared losing her husband if she did not produce a boy. The reasons behind this desire for children of both sexes will be discussed below.

Other

There were other reasons less commonly given for why respondents desire children. Some wanted to have children because it is a natural process. Participants felt it to be a normal way of life, and that pregnancy and birth are natural experiences for women:

> *(Positive man): Giving birth is natural – we were born so have also to give birth to other people [Laughter].*
>
> *(Negative woman): I want to give birth because as a woman if you don't give birth it is as if you are not a woman even when you are married...*

Respondents also wanted children because they make them feel happy. Examples of this include the happiness a parent feels to see their child playing, the pride they feel to see their child grow and the companionship a child offers a mother at home.

The insurance and replacement strategies were also reported as reasons women wish to have children. Female respondents reported these desires themselves while a male respondent noted women's common use of the insurance strategy:

> *(Negative man): What makes women want to have many children is – women are always worried thinking that any time some of the children will die so she has to have many so that if others die, then some can stay.*

Some female respondents reported wanting children to help them with domestic chores. Others suggest religion as a reason why people wish to have many children, as the Catholic Church does not support the use of family planning. Reasoning based on partner's desires and problems with family planning were also offered. These are discussed in the sections that follow.

3.1.1.2 Factors that limit childbearing/family size

Economic concerns

By far the most common reason given for the decision to stop childbearing was the inability to properly care for more children. These concerns have an economic basis – poverty was frequently cited reason for the desire to stop childbearing:

> *(Negative woman): What makes me stop giving birth is poverty - it needs you give birth to children you can afford to look after not to have many and they suffer.*
>
> *(Negative man): I want to say that people should have the number of children they are able to look after. For me I would prefer four children – two girls and two boys, at least those ones you can work hard and cater for them, but if I was rich I would have six children.*
>
> *(Negative man): ... I will not have more than four children because I know how much income I have so I cannot go beyond four children.*

Participants worried about being unable to provide their children with material goods including food, property and clothing. They also expressed concern about their ability to improve their children's life chances, with enough money to ensure access to education and health care. These concerns are highlighted in the following quotations:

> *(Positive woman): Taking care of the children – like when you have many children you find others are not even going to school because you have no money—others are not healthy, the feeding is poor but if they are like two at least – though you are poor you can manage to look after them.*
>
> *(Negative man): You have little or no income at all and you are not in position to look after many children, that is why we have decided to have few children – those that we can be able to take care of, be able to take them to school, feed and dress them.*
>
> *(Negative man): I also say one should have the children he is able to look after - you can have many children, you fail to feed or cloth them, you are not able to treat them in case of any sicknesses – people should have children they can manage to take care of and they grow up healthy.*

Child Mortality

Child mortality was mentioned as a factor that limits family size. Although the insurance and replacement strategies were often utilized, some respondents noted that it was still possible to remain with few children due to child mortality:

> *(Positive woman): Children --- everyone would like to have them but then you can produce them and some die or even they can all die and you remain with none – but all that is God's plan.*
>
> *(Positive man): Now – that's God's plan, you can even give birth to 10 children but if it's not God's plan that they will live – they all die and maybe you produce 2 – 3 children and they live. So as a person can have any number he wants but it's God who gives and takes -*

Infertility

Infertility was also mentioned as a reason why individuals do not have their desired number of children. However, as discussed previously, it is quite common for infertile couples to seek children outside marriage so it is unlikely that infertility is a major factor limiting childbearing.

3.1.1.3 Cultural Norms

Ideal family size

When participants were asked about their desired number of children responses ranged from two to ten. The vast majority of participants wanted between two and six children. When asked if they believed people were able to achieve their desired family size, the responses were split. While some participants felt this was the case others recognized barriers that kept people from having their desired number of children. Some participants reported individuals ending up with more children than they desired whereas other participants reported people having fewer children than they wanted:

> *(Negative woman): I see that nowadays people get families which they don't desire because for example you find a person having about 10 or 8 children and cannot afford looking after them, no education, there is no food, the children start suffering and even you see the parents are not okay – they have no income at all, that is why they say that big families are a problem.*
>
> *(Negative woman): I see that having a family with a few children would be good but some of us we try, we have even tried family planning and failed you just see yourself giving birth all the time when you are even poor, so the children start suffering and you also suffer.*
>
> *(Negative man): For me I would prefer four children – two girls and two boys, at least those ones you can work hard and cater for them, but if I was rich I would have six children.*

Male/female differences in fertility desires

When asked if it is men or women who desired more children, the responses were about equally split. However, it may be that men and women desire children for different reasons. For example, the most commonly cited reason for men wanting more children was that they felt the need to increase the size of their clan. Women, on the other hand, were more likely to want children to keep them company or to prevent their husband from taking another wife:

> *(Positive man): It is the man who mostly forces the woman that they should have children because he wants to expand his family and clan.*
>
> *(Negative woman): ... us women we want children because every child stays with the mother not the father, you play with her/him you also feel happy as the child calls you Mom.*

> *(Positive woman): The woman refuses saying let me give birth until – it is God's plan He will take care of the children [laughter], saying the man might marry other women who will come to share with her the property they have.*

Ideal family composition

Many respondents stated that they and/or their partner would like to an equal number of children of each sex. Both men and women seem to desire "balanced" families. Quotes that reveal this desire are below:

> *(Positive woman): A man wants equal children - like maybe if you give birth to three boys then the girls should also be three and if you have more girls, the man will not be happy and even you the woman will not be happy if you have less girls or no girl at all.*
>
> *(Negative man): Me I would want to have a balanced family - two boys and two girls – that is what I want.*

It is clear why respondents desire male children: boys become part of the clan and inherit land and other possessions from their father whereas girls marry, and leave their father's clan for that of their husband. Thus, without boys, the size of the clan is reduced in which case possessions may be taken by those from other clans:

> *(Positive woman): Someone can give birth to only girls and people will start saying that women has destroyed the clan and another can give birth to only boys and they say that one has expanded the clan. That is it.*
>
> *(Negative man): You asked why women want to have many children – it is like this, for example a woman has five girls, she will want to continue giving birth until she gets a boy who will be the heir.*

While reasons for desiring girls were ambiguous, they possibly reflect the dowry of money and livestock paid by the groom to the bride's family before marriage. Regardless of the reason it is clear that both men and women still desire female children:

> *(Positive woman): A man wants equal children - like maybe if you give birth to three boys then the girls should also be three and if you have more girls, the man will not be happy and even you the woman will not be happy if you have less girls or no girl at all.*

> *(Negative man): Me I would like to have five children but at the moment I have four children and they are all boys and I want to look for the fifth and I pray that it is a girl but if he is also a boy I will just stop because I don't want more than five children - [Laughs].*

Fostering

Respondents from the HIV negative focus group sessions were queried as to the norms with respect to looking after non-biological children. Two situations were encountered: one where the adopted/fostered child belonged to their sibling and the other where the child was from a spouse's previous union.

Respondents were unanimous in supporting the idea of looking after their brother's or sister's child. Two respondents had themselves raised one or more children of their deceased siblings. Everyone felt it was important to treat these children well and care for them as though they were their own:

> *(Negative woman): Your sister's child is also your child so if the mother has died you have to take that child as your own look after him/her feed, educate, give medical care to him/her as your own.*
>
> *(Negative man): Looking after your brother's or sister's child is very good and if maybe they have died – it is indeed good. For example, me I am looking after the children of my two brothers who died – I have nothing to worry about – they are also like my children.*

There were also some respondents who wholeheartedly supported looking after the children from their spouse's previous relationship. However, the reasoning behind caring for these children tended to differ from that given had they been children from within the family. Female participants stated that they would care for their husband's children for God's sake, because the child is not at fault, or because they were fearful of the wellbeing of their own children should they die. Men, on the other hand, tended to report that they would look after these children as part of their obligation upon choosing to marry a woman who already had children. Although it was generally considered, important to care for these children many reported it would be difficult, if not impossible, for them to ever feel as though their spouse's child was their own. Some women reported that even though they would be willing to look after this child they would feel jealous of him/her. Men reported that they would also make sure to have a child of their own with their spouse to ensure they are providing for their own child as well as their spouse's child:

> *(Negative woman): No—they shouldn't lie though you look after him there is at least something of jealous within you – the man might say anything and you feel jealous – but for you, you work for God's blessings but it will not feel like your sister's child.*
>
> *(Negative woman): ...you look after him/her but with jealous – saying though I look after him/her - tomorrow they will not know me [Laughter].*
>
> *(Negative man): Yes you look after that child but its better if I also have a child so that maybe if I am to buy a loaf of bread then I know my child is also having a share on that bread – then there I feel very happy.*

There was a preference for female children if fostering a child from outside the family. Such preference guards against property being taken by boys from outside the clan:

> *(Negative man): Most men – if they are to look after a child that isn't theirs, they prefer a girl child because the boy after he has grown he wants his share on the property. So if a woman has a girl child I accept to look after her but a boy – I rather also have my own child.*
>
> *(Negative man): You see – the girl will get married and she goes away but the boy will want property.*

Delivery Practices

Respondents and health workers were unanimous in the opinion that most women deliver their children at home in their village. This is done either alone or with the help of the husband, neighbour or Traditional Birth Attendant. However, some respondents noted problems associated with delivering in the village and recommended that women instead deliver in a hospital or clinic:

> *(Positive man): Delivering is in different ways – some mothers deliver safely and others are operated upon. So you cannot know what will happen so it is better to give birth in the hospital.*
>
> *(Negative woman): ...I think that one should give birth in the hospital because the baby can come out in a bad position and you find it difficult and you can both die but in the hospital they can help you in case of any difficulties.*

Some respondents mentioned that it was especially important for women to deliver in the hospital if they have had prior problems with childbirth or if they are HIV positive (to be discussed in the final section).

Responsibilities

During the course of the focus group sessions, it became apparent that men and women have different roles with respect to childbearing. Men are responsible for the financial aspects of raising children. This includes saving money for a hospital delivery in case of obstetric emergency as well as the financial aspects associated with raising children. Women, on the other hand, are the direct caregivers for their children, attending to daily needs and spending time with them at home.

3.1.1.4 Reproductive Decision-Making Process

Planning

Respondents were split as to whether or not they planned their pregnancies. Some reported stopping family planning in order to conceive whereas others had problems with family planning or had never used it and therefore became pregnant unintentionally. Planned pregnancies were reported to be more common now than in the past, but certainly not the norm.

Discussion

Discussion between partners about reproductive decisions was also reported to be more common of recent than in the past. However, it is still not a given that a couple will have a discussion regarding the number of children they wish to have. Differing views on this topic are noted below:

> *(Negative man): No – she is meaning that before the woman gets pregnant do the two of you as man and wife come to an understanding – and me I say no because if I feel I want to have a child then I make the woman pregnant I don't have to ask for her permission – [Laughter].*
>
> *(Negative man): Me I think this issue should be for two people – both man and woman should sit down, come to an understanding to have two, three children. They should both agree.*

The consensus appears to reflect how the wishes of the husband and/or the dynamics of the relationship dictate whether such discussion will take place:

> *(Interviewer): Now talking about discussion – is it easy for a man to call the wife that they sit and talk about how many children to have? (Negative woman): XXX speaking – not all men, just a few. (Interviewer): So you cannot find a man and wife sitting down together to discuss...? (Negative woman): Yes, it is up to a few men, most men don't mind they just produce like maize.*
>
> *(Negative woman): Yes, that is if they are peaceful at home, there is an understanding they sit and talk about how many children to have, those they can afford to look after...*

Control Over Reproductive Decisions

When asked who is responsible for deciding how many children a couple will have, three answers were given: the husband, both husband and wife together, and God. None of the respondents reported the wife to be the primary decision-maker.

By far the most common response to questions regarding RDM was that the husband makes the decisions. The reason for this is because the man is the wage-earner and, therefore, the head of the household. He is expected to determine how many children he can afford to support given his income and instruct the woman to bear accordingly:

> *(Positive woman): [The man] – in most cases, because if a woman starts saying "we should have these children" – three or any number – the man will ask you "where do you work, it is you to provide for them?"*
>
> *(Negative woman): The man wins because he is the head of the family, he is the one who plans for the family and he knows his income.*
>
> *(Negative man): You see I the man I am the household head, am the one who looks for the money, I know how much money I have so I will tell the woman to continue giving birth according to my income and if she refuses I divorce her and marry another woman.*

Some participants reported that both spouses decide together the number of children they will have. This seems to be an idealized situation, however, that occurs rarely. For example, when these respondents were asked what would happen in the case of a disagreement, all said the man would win except for one who said the women's opinion would be "considered".

Some respondents, mostly female, named God as the one who decides because He is the one who gives and takes children. Infertility and child mortality were cited as examples of God's ability to affect family size. Some women do not take the decision to stop childbearing into their own hands, but rather wait until they naturally stop conceiving, as they believe this to be God's decision to make. The examples below illustrate the view that reproductive decision-making lies with God:

> *(Negative woman): I think it is God who gives when He decides that you give birth you do – you can even marry a woman and fail to give birth - for you, you want to but then it fails. So I say it's God who gives births.*
>
> *(Negative man): ...women want to have children because they say that God gave them that gift that they should produce until God decides that they stop, that is when they will stop [Laughter].*

3.1.2 Family Planning

3.1.2.1 Norms

Norms of use

While the majority of patients from the focus group discussions reported using family planning at some point in their lives, there were also a number of participants who never used it. Furthermore, some participants reported that they had been using family planning but decided to stop for various reasons (discussed in the 'barriers' section). It should be noted that study participants are more likely to be family planning users than the average rural citizen as they are all health care users. Participants and health workers reported that people in the villages are often hesitant to use family planning.

Decision to use family planning

The decision to use family planning usually requires the consent of both partners. In particular, it is important that the husband agrees to use family planning; if he does not, the wife will either abstain from use or resort to covert use.

> *(Positive woman): The man will not let you decide – even if you want to use family planning, he will not let you...*
>
> *(Positive woman): It is not easy – if you the woman accepts but the man refuses you cannot use [family planning].*

> *(Negative man): With that question, me I say it is the man to decide because he is the household head—he can decide and tell the wife "those children are enough let us now start using family planning" and the wife will follow what the man has told her.*
>
> *(Health worker): [Family planning use is] done in secret, most of the clients do it without...notifying their partners. And once they know they are usually mistreated by their partners.*
>
> *(Positive woman who became pregnant): ...the man wants children most because as a woman when you say "I am going to start using family planning" the man will say "out of my house there is no family planning in my home ------ (laughter) I do not want family planning". And if you insist he sends you away [divorce], so you also decide to leave family planning and get pregnant again and again...*

However, some respondents noted that even when the husband wants to use family planning the wife's consent is also usually necessary:

> *(Positive woman): ...sometimes the man will advise the wife to start family planning, that they should have a few children and the woman refuses – she continues giving birth.*
>
> *(Negative man): I say yes it can be easy if only the couple agrees because one cannot use family planning when the other hasn't accepted but then in the villages some people fear family planning saying some people have used it and it affected them. So the women decided not to use family planning, even though the man accepts the woman might refuse because maybe she knows someone who used it and it had side effects. Most people don't believe in using family planning.*

Participants recognized the need to use family planning in order to space their children. Some reported having seen children who resemble twins because they were born within a short period of time which prompted them to use family planning:

> *(Positive woman who became pregnant): ...family planning is good because it helps you space the children instead of having a child before the other one is even a year and you find all the children are like twins-----*
>
> *(Negative man): ...in the villages people give birth almost every year – you find children you can think they are all twins, an example is mine I have my first two children and they are almost the same age so we decided to use family planning...*

Methods

According to health workers at the Rwimi Health Centre, three family planning methods are dispensed: oral contraceptive pills (two types: estrogen/progesterone and progesterone only), injectables (depo provera) and the male condom. Respondents confirmed that OC pills, injectables and condoms were also the three methods available at the Bigodi Health Centre. These methods also tend to be the ones sold in local shops. All of these methods were mentioned in the focus group sessions by the respondents, indicating that most if not all participants were familiar with them. Participants noted that OC pills, injectables and condoms were the most widely used methods of family planning which is understandable as they are the most widely available ones. However, some tended to be more popular in certain communities:

> *(Interviewer): But what do most people know? (Positive woman): Injections.*
>
> *(Negative man): Most people in the villages usually use Pillplan that it is the cheapest, and there is also Injectaplan but then people don't usually use it because it has side effects – it makes women bleed a lot.*
>
> *(Negative man): In our village most men use lifeguard condoms.*
>
> *(Positive woman who became pregnant): As we are talking about family planning in the village – very few people use condoms--- you hear them saying though they are given to them they don't use them – they throw them away – many people do not use them----*

Some methods not available in local health centres were also mentioned, including Norplant, tubal ligation and IUDs (sometimes locally referred to as "IUCD" or "overturning the uterus"). To access these services, patients need to travel to the hospital in Fort Portal, which can be more than an hour away by public transportation. Participants from the Bigodi region mentioned that doctors occasionally travel to their villages to perform some of these services (such as Norplant insertion). These methods were used by very few participants and are much less common in the villages than the methods discussed previously.

Abstinence, withdrawal, natural family planning (safe days) and local herbs were also mentioned as family planning methods. These methods do not require any supplies except for the herbal method whereby the herbs can be retrieved from the village or surrounding area. The herbs are obtained from certain women in the village who know how to use them. They are either chewed or made into a tea – reports varied as to how often and how much to take. Since they do not require travel away from the village these methods are convenient for participants to use, despite their ineffectiveness. Two respondents mentioned that they used the herbs and two others mentioned using natural family planning. It is not clear how popular these methods are with others in the villages.

3.1.2.2 Barriers

Side effects

By far the most commonly mentioned barrier to family planning use was the risk of side effects. This problem was raised in every focus group session with participants initiating such discussion before it was mentioned by the interviewer. The most commonly mentioned side effects were heavy bleeding, headache, weakness and dizziness. They were most commonly associated with both injections and pills. These problems were seen to be a huge obstacle for village women who work long hours farming everyday. Their concerns surrounded the limitations these side effects placed on their ability to dig in their gardens, which could then result in a food shortage for their family:

> *(Positive woman): Family planning makes one feel dizzy and it doesn't want someone to work so hard and for us in the villages, we dig till even two o'clock in the afternoon and by the time you go back home you are all feeling headache, having nothing to drink, no milk – you lose weight – getting weak.*
>
> *(Negative woman): The problem is that when you use those drugs you are all weakened and you have to dig. And if you sleep without digging then that means there is no food at home.*
>
> *(Negative man): In our village people aren't using family planning because they are farmers and they do a lot of work, digging, and people on family planning are not supposed to do a lot of work, so they fear using them because they have to work, dig.*

> *(Positive woman who became pregnant): ...when you start family planning you won't be able to dig – you start feeling dizzy, constant headache and bleeding – there is no one who will be peaceful while on family planning and her work is farming, no, only those in towns, they are the ones who are on family planning and are peaceful because they don't dig.*

Health workers agreed that these side effects are indeed common and are a problem for women in the villages. One stated that heavy bleeding could be treated but that the patient would be restricted from using that method because the hemorrhaging would resume if they restarted with that method. Another health worker said that heavy bleeding does occur but might be related to STIs in combination with family planning use, and thus could be reduced or eliminated if patients were tested and treated for STIs.

Another commonly cited side effect was vaginal dryness which was associated with injections, pills and tubal ligation. The sexual fluids were reported to be very important in the sexual practices of western Ugandans. Thus, dryness was seen to be a problem because it caused conflicts within the marriage that can lead to infidelity or divorce:

> *(Negative woman): When I used injections, I all dried up – concerning the sex issues...*
>
> *(Negative woman): You find a woman very dry as a piece of wood, weak--- you end up stopping the family planning and getting unwanted pregnancies. The man then abandons you and you suffer with the children alone. [...]*
> *(Interviewer): Ahhh (yes) - especially in this Western region, those vaginal fluids play a lot during the sexual act.*
>
> *(Negative woman): ...with the pills they cause drying up which bring conflicts between the man and wife and the man stops you from using them again and you find yourself pregnant again and again.*
>
> *(Negative woman): But if a man is a womanizer then he abandons you for other women who are not dry.*

Other less commonly reported side effects include weight loss/gain, fast heartbeat, high blood pressure, abdominal pains, amenorrhea, vaginal pain, difficulty breathing, hot flashes and itchiness. Women were always the ones reporting personal experience with side effects. Although this was expected for the hormonal methods, it still should be noted that quite a few women (but no men) also reported side effects with the male condom.

During the course of the focus group sessions it became apparent that many of the women who expressed concerns about side effects had never used family planning themselves. It was quite common for women to fear using family planning because of rumors of side effects rather than personal experience. One health worker explains her views on this situation:

> *(Health worker): And I think why most of the people don't turn up for family planning is because they fear side effects. And even those who have not had the side effects yet, they hear rumors, even if they have not used it someone has told me since I used it I will bleed, maybe, so don't even turn up to get it at all. [...] When a woman comes and tells me about something that has happened to me after using family planning I will take it more serious than when I go to health workers who will tell me that everything it may happen to me (inaudible) may not happen to you. I will take something that has been told by a friend in the village (inaudible) health worker and I will not rely on the health worker. So they always are more oriented to the community than the health workers, they think we are just promoting our work, services...*

Women called for the development of new family planning methods that are free of side effects. Alternatively, they asked for a machine to test their blood to know which methods will not be acceptable for them to use. They felt helpless because they wanted to stop childbearing but felt that in order to do this they would have to submit themselves to using methods that would have a detrimental effect on their health.

Stigma/misconceptions

There were many misconceptions associated with family planning, one of the most common being that condoms cause cancer. Some participants cited the lubricant on the condoms as the cancer-causing agent:

> *(Positive woman): People say these condoms cause cancer and now some of us fear using them, that when you use it a lot it affects the uterus.*

> *(Positive man): Yes – why they say it causes cancer is maybe because of that watery – oily substance that the condom has, maybe that is why they say it causes cancer.*
>
> *(Negative man): Other women say that oily substance on the condoms makes them get cancer that is why they refuse to use condoms.*

Some women also noted fears that OC pills would cause problems with the uterus:

> *(Negative woman): We hear that when you swallow a lot of pills in the end you suffer from cancer of the uterus.*
>
> *(Negative woman): I also heard that when you use family planning, mostly the pills, they affect the uterus and they can remove it.*

Women also expressed fears that condoms could fall off and harm their stomachs:

> *(Negative woman): --- a condom can even slip off and it makes a woman's stomach swell – you now have to go to hospital for operation.*

There was also much concern that family planning could cause infertility, abortion, miscarriage and/or fetal abnormalities:

> *(Negative man): ...there is a woman who used the pills but I think she used them badly and she got pregnant and had miscarriage and she got very sick, so people say I will not use family planning, you see what has happened to the other woman—that is why people have refused to use family planning.*
>
> *(Negative man): Others say that when you use pills and then stop and get pregnant you give birth to an abnormal baby.*
>
> *(Negative man): Me, I heard over the radio that when you are a young girl, for example in senior one, and you start using family planning that by the time you are 25 years and maybe you want to have children you will not get pregnant because these pills and injections will have spoilt you – that is why people are not using them.*
>
> *(Health worker): ...some people believe that family planning is there to help them abort. Someone comes and says maybe I know a thing to abort but people told me when you start on the injection you can never get pregnant. So they think because it is the reason why they never get pregnant it can help them what? In abortion.*

There is also evidence of stigma associated with condoms. For example, some said that it was not acceptable to use condoms in a marriage but rather only with outside partners (mentioned mostly by HIV negative respondents). As well, there is a saying that condoms are bad because "you can't eat a sweet when it's wrapped", meaning that you don't get the full sexual experience when condoms are used:

> *(Negative man): Even some women – when you tell her that you are going to use a condom, she will ask you if she is no longer your wife but a prostitute – they cannot accept, they say that condoms are for women outside marriage and prostitutes.*
>
> *(Negative woman): ...most men say I cannot use a condom with my wife – has she become a prostitute? [Laughter]*
>
> *(Interviewer): --- why don't people want to use condoms? (Positive woman who became pregnant): they say they cannot eat a sweet in it's wrapper---- (laughter) That's true - that they cannot eat a sweet while it's wrapped----(laughter).*

These misconceptions and stigma appear to be fairly widespread. However, there were participants who recognized these problems to be false and who do not believe the rumors associated with family planning.

Knowledge/counseling

Respondents were all aware of the purpose of family planning and of the most common methods. However, the participants were all health care users and there was concern noted that others in the villages were not sensitized about family planning which might explain why they are not using it:

> *(Negative woman): There are some men in the villages who even don't know how to put on condoms [Laughter].*
>
> *(Health worker): And especially from rural areas they still lack education, they lack more information. [...] We need more, to create more community awareness. (inaudible), sensitize more people. Although we are being helped by the community volunteers but people still need more information, especially in the rural areas.*

Some respondents suggested that health workers and/or community leaders, such as politicians, become involved in family planning education and promotion in the villages. They believe that many villagers will not travel to health centres for services due to cost or stigma and that bringing information and supplies to the villages would increase family planning use in these areas.

Most respondents stated they had enough information regarding family planning and that their reasons for not using it were related to stigma and side effects rather than a lack of information regarding contraceptive options:

> *(Positive woman): Me, I know all about family planning but I just don't want to use it.*
>
> *(Negative woman): That is what has kept women in the village conceiving every year and people are wondering if they don't know about birth control – they know, but the problems.*

Partner opposition

Partner opposition was a common reason for not using family planning. As noted above, opposition from one spouse generally negates family planning use, particularly when it is the husband who objects. While both men and women were found to oppose family planning they generally did so for different reasons. Men were sometimes said to refuse family planning because they want more children than their wives or because they have feelings of ownership over their wives, having paid a bride price:

> *(Positive woman): Even some men don't want them—they say, "this is my woman, I paid my money (bride price) for her, so sex has to be live – no condoms".*
>
> *(Positive woman): Sometimes the man is found positive and the woman negative but then you have not had children for him, he will not accept to use condoms and when you have sex without condoms that is a must, the woman will get pregnant.*
>
> *(Health worker): Husbands, husbands. They tell you husbands don't like family planning.*

Women tended to refuse to use family planning because of stigma and fear of side effects:

> *(Positive woman): It is us women who mostly refuse [condoms] because of that fear of diseases.*

> *(Negative man): It is true an example is me – I came here with my wife in February this year – with my wife we tested and they told us to use condoms, then I asked the doctor if its true the condoms cause cancer and he said no but when we reached home my wife refused saying she cannot each a sweet when it is wrapped, I better go back home (divorce). I also decided to leave the condoms. After completing the dose of some tablets they have given me that is when I had to have sex with my wife – she refused condoms [Laughter].*

Cost

All family planning methods carried by the health centres are dispensed free of charge. The respondents seemed to be aware of this, however some noted that even though the services are free it can be a challenge to pay the transport fees from their home to the clinic. However, even when people do need to resort to buying contraceptives in the shops the prices are relatively inexpensive. Pills were reported to be between 300 and 1000 shillings (less than $1 Canadian) for a package that lasts one month. Injectables were 1000 shillings for one shot, which lasts for three months. Condoms are probably the most expensive method with the price ranging from 200 to 2000 shillings for three, depending upon the brand. These costs are relatively inexpensive, even given the low income of the participants. This, coupled with the fact that family planning is free at the health centres, indicated that cost is not a major barrier to use. Furthermore, none of the participants mentioned not being able to use family planning due to financial constraints.

Other

Other barriers to family planning use that were mentioned included inconvenience, loss of enjoyment of sexual acts, method failure and religion. Inconvenience was generally mentioned in reference to forgetting to take pills everyday. Loss of enjoyment tended to be associated with condom use or vaginal dryness caused by pills, injections or tubal ligation. Method failure was noted in reference to forgetting to take pills and then conceiving. As well, the local herbs, while touted to be very effective by some participants, were reported to be quite ineffective by others. Natural family planning was noted to be somewhat ineffective because avoiding sexual contact for much of the month was not always deemed practical. Religion was rarely mentioned as a barrier to contraceptive use even though many of the respondents were Catholic and not supposed to be using family planning according to their faith.

3.1.3 HIV/AIDS in General

3.1.3.1 Testing

All participants, with the exception of the health workers, had tested for HIV. They gave various reasons for their decision to test. Most of the positive participants tested after seeing their partner's or their own health fail, experiencing the death of a child, or noting that their spouse's previous partner died. One health worker noted that the number of people coming for testing has increased dramatically after ART became available because people then saw the benefits of knowing their status. Those who had already tested were sometimes able to encourage others in their village to test:

> *(Positive woman who became pregnant): For us when we tested – people at first used to make fun of us, laugh at us but now very many come to us seeking for advice and very many have also tested following our advice.*

One reason why many women test is because it is a component of the antenatal care program. However, while testing pregnant women allows for the treatment of the mother and PMTCT it may also have a negative effect: one participant claimed that mothers do not come for antenatal care because they fear being tested for HIV.

It was reported that many people in the villages, especially men, still refuse to test. One health worker said that men's refusal to test for HIV was her biggest challenge because they are the ones who make household decisions. If they do not know their status then they cannot make sound decisions that take their HIV status into account. Some participants said that men often do not test because they fear to know their results:

> *(Negative man): Me I associate with very many people in the village and as men when we talk about HIV testing, most of them say they fear – they are still childish, enjoying life -- they say that when they test and they are positive they start getting worried and die very fast – I die of worries - so that is what makes men fear to come for testing.*

Lack of knowledge in the rural areas was also reported as a reason for not testing for HIV. As well, people are often not tested because they cannot afford to take time away from their farming and/or pay the transport costs to the health centre. Some participants and health workers recommended community outreach programs to overcome these obstacles:

> *(Negative man): ...let us have you people come in the village – there are many who would like to be sensitized but then they say this place [health centre] is far and besides that people are farmers, they see coming here as wasting a lot of time but if the services were in the villages that a person can have some little time off his farm but coming here is wasting the whole day's work.*
>
> *(Negative man): I support that people always ask what we come for here and even though we tell them they are reluctant. Even they say they cannot afford the transport --let us have the services in the villages – it is really better.*
>
> *(Health worker): I would recommend that outreach health education in the rural areas...by the municipal personnel.*

Stigma is also a factor which inhibits people from testing for HIV. It was reported that people do not come for testing because if they are spotted at the health centre others will know they are being tested. Decentralization of services to the villages was mentioned as a means by which to overcome this problem:

> *(Negative man): ...let the doctors go deep in the villages – people are willing to test but then they are shy, they say it they are seen coming here they will know they have come to test for HIV but if you go to villages maybe will not feel shy.*

Some people also refuse to test because they think their spouse will blame them for bringing HIV/AIDS into the relationship. Diagnosis can result in divorce; therefore many people either do not test or do not disclose their status to their partner in order to avoid harming their relationship:

> *(Negative woman): It is mostly men who bring this disease to us – for you the woman you just stick to one man while for him he moves from one woman to another and when you get weak and tell him that we should both go and test he refuses – maybe for him he tested and he is on treatment when you don't know.*
>
> *(Negative woman): He fears that if he tells you his status then you can go back to your home (divorce).*
>
> *(Negative man): Some women think - they fear that when I tell my husband he will think I am the one who brought the disease that is why I think most women keep quiet about it.*

> *(Health worker): Okay, when women come here to test when they are pregnant, when they have come for antenatal clinic they will tell you that it's that inferiority complex, they fear to tell their husbands, and especially when they are positive. They would fear to tell their men because men are not be, be ready to swallow it. [...] And in most cases the women tell us "I'm not ready to go and tell that man, he will kill me. He has stopped me from testing, but I have tested, telling him will be a problem".*

Once an individual has made the decision to come for testing they undergo a specific process. At the Rwimi Health Centre this involves group and/or individual pretest counseling, blood testing and posttest counseling. In the pretest counseling sessions the health workers create confidentiality with the client, ask them about their risk factors, explain the testing process, discuss how transmission occurs and provide information on the effects of HIV/AIDS, dispelling any preexisting misconceptions. Following this, the clients' blood is drawn. In the posttest session the counselor reviews what was covered in the pretest and then gives the client their results. They make sure the patient understands and accepts their results and help to show them the way forward. This can include prompting them to come for CD4+ count tests the following week if they are HIV positive and asking them to return for testing in three months if they are HIV negative. Proper nutrition for those who are infected is also explained. Childbearing decisions and family planning are also discussed but these topics will be covered in the later sections. The respondents reported being satisfied that they understood the majority of the information presented to them during their counseling sessions.

3.1.3.2 Treatment

HAART (highly active anti-retroviral treatment) is used to treat patients in the area with clinical symptoms of AIDS and/or a low CD4 count. Patients who are not eligible for HAART are prescribed Septrin, an antibiotic that helps to manage opportunistic infections. HAART and Septrin are both given free of charge at the health centres. In addition, Septrin can be bought from local shops. The main concern expressed during the sessions was that the services be continued. Both participants and health workers expressed fears that these life saving drugs would not be available in the future.

HAART had been available in Rwimi for more than nine months at the time the study was conducted and is delivered to the patient's homes by community volunteers. Patients in Bigodi, on the other hand, must travel over one hour by public transport to either Rukonyo or Fort Portal to receive HAART. There are also sometimes shortages of Septrin at the Bigodi Health Centre which means that patients not on HAART also have to travel far from their homes to access treatment. This was noted to be a problem for patients who could not afford the time and money required to collect their drugs:

> *(Positive woman who became pregnant): I am asking that here at the Health Centre they should help us and especially us who are sick in most cases they tell us that Septrin are not enough that is also a problem because sometimes we have to buy for ourselves and some of us cannot afford – so we are asking for your help on that and another thing some of us have started on the ARVs and we get them from Buhinga (Fort Portal Hospital) but we reach an extent and fail to raise transport so we are asking you to at least bring the drugs nearer to us – you find at times the transport is high - you have young children at home, some are sick, they have to go to school and this really becomes a very big problem.*

There is also stigma associated with treatment. One health worker reported that sometimes the wealthy patients pretend that they are picking up drugs for others rather than admitting that they themselves are HIV positive and on HAART. This can cause confusion and can be challenging for the health workers. One additional problem that was mentioned with respect to treatment is that patients cannot afford food to take with their drugs. HAART is best taken with food or milk and also is known to increase appetite in users, causing problems for poverty-stricken patients:

> *(Health worker): There are some people who are on drugs which have Nevirapine in them, they normally come here saying that they have big appetite... so that when they are not, will it be enough, they say that "you mean I am taking drugs, I have the appetite but we have nothing to eat".*

3.1.4 Childbearing and HIV/AIDS

3.1.4.1 Influence of HIV Diagnosis on Reproductive Decisions

Almost every participant stated that an HIV diagnosis did/would impact their reproductive decisions. Most participants agreed that when a couple finds out they are HIV positive their best course of action is to stop childbearing. Concerns for the health and wellbeing of the parents and child were often mentioned as factors motivating this decision (to be discussed in the following section). Many respondents voiced this desire to stop childbearing and take care of the children they already have in order to avoid causing harm:

> *(Positive man): ...since now we know our status, we should stop on the children we already have, look after them and plan for their future.*
>
> *(Negative man): ...after you test and you are HIV+ that forces you to stop giving birth because you'll have many children and when you die they start suffering or maybe they are also infected – you never know.*
>
> *(Negative man): If I tested and found I am HIV+ definitely my decision of giving birth will change. I will stop because of this reason - the woman will weaken if she is sick and she continues giving birth and the child born is on the risk of getting this disease.*

Stopping childbearing was mentioned as the best course of action for those who already have children. However, if a couple was newlywed and/or did not yet have any children the situation was perceived somewhat differently. While many participants still thought that these individuals should stay without children, some were sympathetic and felt that they could have a small number. In fact, some thought it was preferable to risk the health of the mother or child than to die without having children. Views on how to proceed for individuals who are newlywed are represented in the following quotations:

> *(Positive woman): You can stay without children and be in love with your husband because he knows what has stopped you from giving birth [Laughter].*
>
> *(Negative man): ...me I don't accept that we give birth, if both me and my wife are found HIV+ then we rather start without children [newlyweds] other than leaving the children to suffer – it's not right at all.*
>
> *(Negative woman): ...maybe if they are newly married and they test HIV+ before even having a child, if they see they can afford they can maybe give birth to at least one child or two.*
>
> *(Negative woman): ... if you have not given birth, you also feel you want to have a child – that of saying you are positive won't work, a person will say I rather give birth and the child dies other than being there without giving birth [Laughter].*
>
> *(Negative woman):...if it is like that and we are both sick – we give birth and if we are to die, we die [Laughter].*

Participants were also asked their views on a situation in which both members of a HIV positive couple have children from a previous spouse, but not with one another. Some participants said these people should not have any more children, however, others said that it would be very difficult for this couple to remain without having children together:

> *(Negative man): ...it's good if you have decided to stay together without children so long as you both had children before – there is no problem you can stay together.*
>
> *(Negative woman): ...though I already have children but still I would want to deliver for my new man – that issue of being sick will come later – [Laughter].*
>
> *(Negative man): ...if I marry a woman and she already has her children I also have mine, but she is still healthy and beautiful, I rather have with her one child so that even though we die we know we have had a baby together [Laughter].*

Thus, rather than completely stopping childbearing it was often noted that having smaller family sizes was the best course of action for HIV positive couples:

> *(Positive woman): Yes, I would have even six but now since I know my status why should I have all those children? I can have more that three? No.*
>
> *(Negative man): About that, me I say that if me and my wife are newly married and we both test positive-- yes, its good to have children but then we can at least have two children because we are both sick so we have only those so we can be able to look after them so that by the time we get weak the children have at least grown, they know their property and can take care of themselves.*

Some participants were adamant that HIV infected people should not have children. They stated that it would be better to end the marriage than have children if positive. One respondent said she would not marry at all if she was diagnosed:

> *(Positive man): If we both have children we can decide not to have more and if you the woman refuses, I can let you go as long as I already have children.*
>
> *(Negative woman): It is up to your life – you should care about your life as a woman because if you die the man can get other women – me I won't give birth and the man finds other women.*
>
> *(Negative woman): I say that I don't get married, I just stay alone because even the baby I want to have I may die and leave him/her – I don't get married.*

Another reason why HIV positive individuals limit childbearing is because they lose their sexual desire. However, it was reported that this desire returns with ART which can then motivate people to resume childbearing.

Some participants stated that it was okay for HIV positive individuals to continue childbearing only if they prescribe to certain interventions which can reduce the risk of harm to the mother or the child. These interventions include seeking medical care and PMTCT services as well as properly spacing the children (to be discussed in sections that follow).

Participants reported wanting to have children when HIV positive for the same reasons that Ugandans generally wish to have children. Thus, although they might fear the repercussions of having children when positive this does not always diminish the cultural reasons for having children, such as wanting to increase the clan or to have children of each sex. Examples of still wanting children to fulfill cultural expectations, find a child of a different sex and appease the partner are shown in the following statements:

> *(Positive woman): ...So when I was pregnant with this child I decided to test and I was found positive. I would have stopped giving birth but then I have been producing only girls and I have only one boy – the man is saying his property will get wasted but then I want to wait until at least when this child is about four years then I can again give birth.*
>
> *(Positive woman who became pregnant): ...after finding out that I am HIV+ I had not wanted to produce again, but the man refused and he forced me to get pregnant again...*

Three of the five women who became pregnant following their HIV diagnosis did so by accident. Thus, even though a diagnosis leads to wanting to stop childbearing unplanned pregnancies may be a limiting factor in achieving fertility reduction for those who are HIV positive. Failure to use family planning was sometimes mentioned as the reason for unintentionally becoming pregnant following an HIV diagnosis.

It was reported that some HIV positive individuals have children either because they do not know their status or because they have not disclosed it to their partner. Participants gave these reasons for why HIV positive individuals continue bearing children:

> *(Positive man): After testing of HIV and you know your status, then you decide on what to do – have 2 or 3 children. But then when you have not tested to know whether you are sick or not you just produce anyhow.*
>
> *(Negative man): Even men after knowing they are sick they also fear telling their wives, they will also just keep quiet and keep on giving birth.*
>
> *(Health worker): ...one problem we face, it is women who have come for testing. And if they are positive and they may not be in position to want anymore children but the husband may not be ready to participate. So, at the end of the day he may get that woman pregnant again. Even if it is against her will. So if we get a chance of getting the husband as well we advise them and they take it but in most cases we don't get the men.*

A startling number of participants (including those who were HIV positive) stated that they did not have enough information with respect to childbearing if HIV infected. Often individuals were unsure about what to do in this situation and wanted more information from health care providers on this subject:

> *(Positive woman): Giving birth, I still want to but when we tested and found me and my husband were both HIV+ and that time there was a training here about reproductive health, so I came and attended to know if I can go on with giving birth or totally stopping – I have not yet decided.*
>
> *(Negative woman): Now me I am asking what if I get that man in my situation but he wants me to deliver for him a baby – what do I do?*
>
> *(Positive woman who became pregnant): I think we don't have information - the information we have is little but we beg you as nurses and doctors to teach us so we can know more.*

Health workers explained their role in counseling HIV positive people regarding childbearing to be that of an educator rather than an advisor. Protocol states that they provide information about the risks of conceiving and delivering while HIV positive without actually giving patients advice on what they should do. However, many patients and health workers report receiving/giving advice on this topic. It appears that some clients, usually those with children already, are advised to stop childbearing. Those who do not have any/many children and insist on having some/more are advised to seek PMTCT services and to always give birth at the hospital or health centre. Some patients also report being told that they can have children but should limit their family size. Some of the advice given to/received by patients is below:

> *(Positive woman): They told us not to give birth again – after knowing we are positive.*
>
> *(Positive woman): They told us to reduce our birth rate for example if you wanted to have seven or five children, you can at least have three and we should always use condoms.*
>
> *(Interviewer): Um, what specifically do you advise HIV positive clients about having children? [...] (Health worker): It depends. If this client is married and has not had children we advise on PMTCT if he or she has to get children. Or else we advise on condom use, consistent. Yeah. Otherwise if he already has children we really advise on condom use completely because we show them the risk of having children when you are already positive, you are likely to get a child who is positive even though we have PMTCT around. So we really advise them on condom use when you are already positive. But if they insist then you tell them the woman gets pregnant they're supposed to come in for PMTCT.*
>
> *(Health worker): ...you are supposed to just give them the information...not even advise them and then... You're not supposed to advise them, just give them the information... and the person takes up the...takes it in. Because we are told that if you advise and the person goes on your advice then anything that will come out you will be blamed. So...mmm (yes). You just give the information and let the person make the decision.*
>
> *(Positive woman who became pregnant): I tested and I am HIV+ and they advised me that when I continue giving birth I will be weakened and die very fast and I will leave the children with no one to look after them.*

3.1.4.2 Challenges/concerns

Wellbeing of parents

One of the major concerns mentioned with respect to childbearing for HIV positive individuals was the health and/or wellbeing of the parents, in particular the mother. Many participants thought that having a child would cause an HIV positive woman to weaken and/or lose a lot of blood which may lead to her death:

> *(Positive woman): ...I was found HIV+ and after knowing I am sick I saw to it that when I continue giving birth, I will die very soon – even giving birth in villages it affects us as AIDS patients, when you keep on producing that means too much bleeding whenever you give birth and you loose a lot of blood and you*

> *die very fast so I came to an understanding with my husband and we decided to stop producing.*
>
> *(Positive woman who became pregnant): I tested and I am HIV+ and they advised me that when I continue giving birth I will be weakened and die very fast...*

Concern for parents was also expressed in terms of infection or re-infection with the HIV virus which would result from having unprotected sex.

Wellbeing of child

Many participants were concerned that having children when positive could lead to HIV infection of the child. Worries that the parents will die and leave the child orphaned were also voiced. Participants tended to feel that these negative outcomes for the child were reasons to limit or stop childbearing:

> *(Positive woman): For example when you don't know your status you can say I will have my six children, but then after testing positive you give birth and maybe the child dies or you yourself will die and leave the child suffering, that will force you to limit your births.*
>
> *(Negative man): ...after you test and you are HIV+ that forces you to stop giving birth because you'll have many children and when you die they start suffering or maybe they are also infected – you never know.*

One health worker noted that although clients are concerned with these issues they often do not realize the difficulty and complexity associated with raising an HIV positive child.

Lack of concern

In contrast to the concerns noted above, some participants seemed to lack any concern for the possible ramifications of having children when HIV positive. Some were not troubled because they felt that death was normal in Ugandan society and that it can come at any time so there is no reason to limit childbearing when HIV positive:

> *(Positive woman): Me, I am not worried that I am going to die because though this disease hadn't come we are meant to die – death is a must – [laughter], though you have it or not you die – some people die of malaria, - so I don't have any fear that I am sick that I will leave my children – we are all meant to die.*

> *(Positive woman): For example me – anyone can die at any time though sick or not. Now I was going to my garden and the snake bit me - was I expecting that? Death is meant for everyone [Laughter].*

Other participants were not concerned about problems associated with childbearing when HIV infected because they felt that all of their problems would be overcome if they sought medical care. There was an infallible trust in health workers, particularly amongst women who were HIV positive and had become pregnant following their diagnosis:

> *(Positive woman who became pregnant): ...when I got pregnant I made sure I attend antenatal care always until when I gave birth. (Interviewer): So you were not worried in any way? (Positive woman who became pregnant): No - but what I thought is to always come here [health centre] in case of any problem.*
>
> *(Positive woman who became pregnant): I was not so worried because I knew I will deliver in the hospital and will be given a tablet to swallow so I deliver a safe baby.*
>
> *(Positive woman who became pregnant): ...when I got pregnant I did not fear or worry about anything [...] but I said to myself--- the hospital will be the answer to all my problems, so I gave birth in the hospital they gave me some tablet and the child was also tested and they found he is HIV negative, so I felt strong and said I will stop giving birth.*
>
> *(Health worker): Because they know that even the village people know and for them they really have beliefs in the health workers: [...] Yeah, in fact they have that blind faith it's true.*

3.1.4.3 Interventions

When discussing whether or not HIV positive individuals should become pregnant many respondents mentioned interventions that could be taken to reduce the chance of MTCT or harm to the parents. These interventions were described to clients by health workers during the pre and post-test VCT counseling sessions. The participants' knowledge and misconceptions about these interventions is discussed below.

Family planning

Condom use was often mentioned as a means to reduce infection and re-infection with the HIV virus. Health workers stress the importance of using condoms in the VCT sessions and many respondents felt that condom use was necessary for HIV positive individuals:

> *(Positive man): Yes –they also told me I have to protect myself and it is what I am doing – me and my wife we use condoms.*
>
> *(Health worker):...we advise on condom use, consistent. Yeah. Otherwise if he already has children we really advise on condom use completely because we show them the risk of having children when you are already positive, you are likely to get a child who is positive even though we have PMTCT around. So we really advise them on condom use when you are already positive.*

While condom use for HIV positive individuals is very important in reducing HIV transmission it is not a very effective method of birth control. Rather, dual protection is the best course of action for positive individuals. Thus, reports that HIV positive participants switched from more effective methods to condoms were of concern. However, this appears to reflect what participants are being advised by health workers:

> *(Positive woman): Me I have used – I started with the pills but after we tested and found HIV+ we started using condoms.*
>
> *(Health worker): ...all people tested positive are supposed to use family planning. Of course, they're supposed to use condoms. So when you are using condoms you can't conceive. So they are supposed to use condoms, but for those who can't, those are the ones who we advise these other methods.*

HIV/AIDS and family planning services appear to be very well integrated. Clients and health workers mentioned that family planning is discussed during the VCT sessions as well as when clients come to pick up their ARVs or receive other health services:

> *(Health worker): Every woman who comes for PMTCT or antenatal, all those who come for immunization, any woman of childbearing age, if she's on ARV treatment or has delivered we always advise about family planning and child-spacing, it is a must for every woman who is ever pregnant or has been pregnant. Every woman and every pregnant woman is taught about family planning but how they respond is more about them because some of them turn up for family planning, others don't.*
>
> *(Interviewer): If someone comes to pick their drugs and also wants an injection do they just do it all when they see the doctor or the clinical officer or do they go to the outpatient...where is the family planning given? (Health worker): It is being done by the same - the same person.*

Although HIV positive individuals are advised to use condoms there were reports that these individuals were often unable to because of partner opposition, side effects and/or stigma:

> *(Health worker): Given our clients is HIV positive and we advise on condom use and…if it is a woman you will advise her on condom use, she is not the one who is going to put on a condom… she has a husband who has not tested, who you have not even talked to, you have not counseled about condom use, this client may not be in position to use it. And this is a challenge to me, yet I am supposed to protect my client here.*

PMTCT

Some respondents mentioned that it is important for HIV positive women to consistently attend antenatal care and to rush to the hospital should they encounter any problems during pregnancy. They also mentioned that a tablet (Nevirapine) could be taken by the mother to prevent MTCT. Usually, this drug is given to clients at the health centre, but it may be given in advance so they can take it with them if they choose to deliver in the villages. Health workers encourage clients to come in for PMTCT services if they insist on having children after being diagnosed with HIV/AIDS.

It seems many participants believe there is no chance of MTCT if PMTCT services are obtained:

> *(Negative woman): I say that if you are not given birth – go to the hospital and they help you – give you medicine and have a safe baby who is not sick.*

> *(Positive woman who became pregnant): I was not so worried because I knew I will deliver in the hospital and will be given a tablet to swallow so I deliver a safe baby.*

Child spacing

Many respondents felt that if a HIV positive couple wished to have children they should make sure to space them well. Some believe pregnancy should be delayed until the mother is as healthy as possible to ensure the risks of pregnancy-related problems are minimized:

> *(Positive man): If you are sick and I am not then I can first know your health and if you are okay, then I can think about making you pregnant so we can have a healthy child, but if I see you are weak, then I cannot make you pregnant.*

ARVs

Some participants were confident that if a mother is on ART then HIV cannot be transmitted to the child. However, other respondents were unsure what effects these drugs have on MTCT and asked for more information on the topic.

Delivery location

One of the most commonly mentioned interventions for reducing MTCT was to give birth in the hospital or health centre rather than at home in the villages. It is widely believed that this intervention drastically reduces the chances of MTCT. In fact, many participants and some health workers believed that there was no chance of MTCT if the woman gave birth in a clinic or hospital:

> *(Positive man): If you decide to give birth when you are both HIV+ then you should give birth in the hospital so the doctors will ensure you give birth to a child who is not infected.*
>
> *(Health worker): With that system I think in the villages it is more…they are one hundred percent but in hospitals the risks are zero. Because in the villages the way how they deliver chances of getting infection is high.*

The reasons why it is believed that the risk of MTCT is so much higher in the village have to do with sanitary and cultural practices. For example, it was noted that gloves are not used in the villages making the delivery process less sanitary and bringing the mother's blood in closer contact with the TBA. As well, the practice of placing the infant immediately upon the abdomen of the mother is not practiced in the villages. This is seen as a way of ensuring that the fluids from the mother have as little contact as possible with the baby. There were also reports that herbs can be placed in the birth canal to induce contractions which is unsanitary and can lead to infection. Furthermore, there is a process of "sucking the cord" which is very common in the villages but is not practiced in a health care setting. It involves pulling blood through the umbilical cord from the mother to the child before the cord is cut in order to supply more blood to the baby. Health workers believe that this practice increases the chances of MTCT.

The HIV positive women who became pregnant following their diagnosis mentioned hospital delivery as one of the main interventions they utilized to ensure the safety of their children. The health workers noted that quite a few women who know they are HIV positive come to the health centre to deliver their children rather than doing so in the villages as most other women do.

Breast milk alternatives

Some respondents mentioned limiting breastfeeding as a means to reduce MTCT of HIV. Most said that the mother should not breastfeed at all or should only breastfeed for the first three to four months. Some mentioned not utilizing mixed feeding but rather exclusively breastfeeding and then stopping upon the introduction of solid foods. Although this knowledge was quite common, it appears as though HIV positive women might not be able to follow this advice due to poverty; breast milk substitutes were reported to be prohibitively expensive. It was reported that some women substitute cow's milk because they cannot afford formula. However, this becomes a problem because cow's milk has often been diluted with unsafe water and can cause infections in the child which endanger his/her health.

3.1.4.4 Stigma/discrimination

Health Care Workers

All positive women who became pregnant following their diagnosis reported informing all of the health workers they came into contact with during their pregnancy of their HIV status. None of the patients reported any discrimination from these health workers based upon their serostatus:

> *(Positive woman who became pregnant): I was not discriminated at all, we were all handled in the same way.*
>
> *(Positive woman who became pregnant): ...from the time I know I am HIV+ I have never been discriminated against, we are all the same be it here at Bigodi Health Unit or anywhere else, they also welcome me as other patients.*

Community

Participants did report experiencing some discrimination from the community if they were known to become pregnant after knowing their status. They did not take these words to heart, however, and felt they and their child would be fine so long as the health worker's advice was followed. Some reported that those who ostracized them had not themselves been tested and so it was ridiculous for them to be passing judgment when they might well be infected themselves.

Participants who had not become pregnant after a diagnosis commented on those HIV positive people who knowingly became pregnant. Some felt these people should be allowed to make their own decisions, provided they were given all the relevant information to make an informed decision. The most unforgiving words from these participants reflected a belief that those who knowingly become pregnant while positive are illiterate and do not reason. Overall there seems to be some discrimination against these individuals, however it does not appear to be very harsh or widespread.

3.2 Themes

3.2.1 Women's lack of control

One major theme that emerged from the data was women's near complete lack of control over their own sexual and reproductive lives. This includes their inability to make decisions regarding the number of children they wish to have as well as their inability to use family planning if their husband objects. Furthermore, it was often reported that husbands refuse to test for HIV and that women who do test often feel they cannot reveal the results to their husbands for fear of being abused or abandoned. Thus, women are often unable to seek treatment if HIV infected and are unable to protect themselves from transmission as it is men who decide if condoms are used in the relationship. This can lead to a greater number of HIV infected women, more pregnancies amongst positive women and poor health status of all women. Quotations portraying women's lack control over their sexual and reproductive health are offered:

> *(Positive woman who became pregnant):...after finding out that I am HIV+ I had not wanted to produce again, but the man refused and he forced me to get pregnant again, I have one boy child and he said he cannot stop, thought I would*

> *deliver another boy but then I gave birth to a boy again but then me I want to stop.*
>
> *(Health worker): ...and actually another big challenge is men involvement in these issues. Because it seems they are the ones who make the decisions at home and the women have no...nothing to do except to be there to deliver. And they're going through so many problems. And men even don't go ahead to look after these new mothers.*
>
> *(Positive woman): It is not easy – if you the woman accepts but the man refuses you cannot use [family planning].*
>
> *(Health worker): Given our clients is HIV positive and we advise on condom use and...if it is a woman you will advise her on condom use, she is not the one who is going to put on a condom... she has a husband who has not tested, who you have not even talked to, you have not counseled about condom use, this client may not be in position to use it. And this is a challenge to me, yet I am supposed to protect my client here.*

The main reason women were reported to have such a lack of control over decision-making is because they lack economic power. Men control all of the money in the relationship and women fear destitution for themselves and their children if they become divorced. Many are not officially married to their husband and feel they would not receive any support if their relationship were to end. Thus, many women feel helpless and believe the only way to survive is by following their husband's orders. These challenges are illustrated in the following quotations:

> *(Negative man): You see I the man I am the household head, am the one who looks for the money, I know how much money I have so I will tell the woman to continue giving birth according to my income and if she refuses I divorce her and marry another woman.*
>
> *(Positive woman): ...if a woman starts saying we should have these children – three or any number – the man will ask you "where do you work, it is you to provide for them?"*
>
> *(Positive woman): ...we have little assistance, you find you are married to a man but you have nothing, not even a piece of land that you can build a house, no source of income, no job that will earn anything – you rent and have to look for money even getting what to eat is hard – at least if we could get capital to at least start up something that will raise you something.*

> *(Positive woman): Helping especially us women – we don't have even a certificate. The man will abandon you in the house and he will go and marry another woman and some men will leave you and go for prostitutes, he will take the little money you have and you the woman will remain suffering with the children – it is you feeding the children, feeding them, it is you who has to dig – make sure you get them beddings, blankets - really a woman suffers a lot.*
>
> *(Health worker): They are dependent on the men. Most women are not doing any work, they're dependent on their husbands.*

3.2.2 Changing norms

Another overarching theme that emerged from the data is that norms and practices surrounding RDM are changing. For example, participants noted that it is becoming more common for people to discuss with their partner how many children they desire and to choose smaller family sizes. Family planning use was also reported to be becoming increasingly common as was the idea of planning pregnancies. Some of this change appears to be due to the HIV/AIDS epidemic: participants noted that it is difficult to have many children if you are sick. However, some of these changes are attributed simply to changing attitudes and norms that appear to be independent of HIV/AIDS. For example, land fragmentation was frequently noted as a reason why people are now deciding to have fewer children: large family sizes of the past are now limiting the number of children these participants can have because parents need to ensure their male children each inherit enough land to support a family. The following quotations portray the changing norms with respect to fertility desires and RDM:

> *(Positive man): These days you don't give birth to expand the clan, things have changed and the responsibility is on you.*
>
> *(Positive man): Some of us are weak – sickly not like people of some years back, for them they used to produce many children because they had enough property and this disease hadn't come – so they had nothing to worry about, but nowadays that is why we have decided to have few children that we can manage to look after.*
>
> *(Positive man): In the past people gave birth to many children because they had a lot of property but nowadays people just give birth even after knowing they are HIV+ they just want to see children fill in the house not bothering how hard it is to look after them.*

(Negative woman): Now with this generation now we know that we should have few children.

(Interviewer): When do you discuss? (Positive man): Nowadays. (Interviewer): And the days before? (Positive man): Before – you would just hear the woman telling you that she is pregnant.

(Positive man): These days we can plan but in the past you would just hear that so and so's wife is pregnant [laughs].

(Negative woman): I will talk about myself and other people – some people plan and others don't. Now like in the villages – you find a 14 years old child pregnant, I don't think that one planned for it but like me, the way I see the world is developing, I say I have to plan.

(Positive man): In the past there was no family planning.

Chapter 4: Discussion

Validity of the Study

The validity of the study can be assessed by comparing the results from the quantitative and qualitative portions of the study. For most findings the results from each study portion are in agreement, as is the case for the main finding that an HIV diagnosis causes people to want to stop or limit childbearing. As well, the strong influence of side effects and stigma in limiting family planning use and the common belief that MTCT is impossible if the mother is on ART and/or delivers in the hospital are apparent from both the qualitative and quantitative data. There were, however, some discrepancies in the data. For example, the quantitative portion of the study found that virtually all of the HIV positive participants disclosed their serostatus to their partner, whereas non-disclosure due to fear of divorce or abuse was mentioned as being common in the focus group discussion sessions. Participation bias and social desirability bias are possible reasons why non-disclosure of HIV test results may have been underreported in the semi-structured interviews. Another discrepancy we found was that only one of the thirteen women who became positive after her diagnosis reported planning her pregnancy during the interview sessions but two reported a planned pregnancy in the focus group discussion session. Since all focus group respondents in this session had been interviewed previously there is at least one participant who made an erroneous claim either during the interview or focus group session. This may be due to social desirability bias or misunderstanding of the questions asked.

Overall, we are fairly confident with the data quality and believe that erroneous findings are few. As always, however, it is best to take the results of this study in conjunction with data from other studies in order to obtain the most complete picture of reality. Our study results are discussed below in reference to other findings from the literature.

Fertility Desires in General

The 2000/2001 DHS showed that the mean ideal number of children for all Ugandan women was between 4.1 and 6.4, whereas the total fertility rate was 6.9 (Anonymous, 2004). Participants who were younger and/or had fewer living children desired fewer children than those who were older or had more living children (Anonymous, 2004). Our results agree with these findings: the average participant desired 4.6 children (95% CI: 4.4-4.8). Similarly, we found that younger participants and those with lower parity desired smaller families. We also found that HIV positive individuals tended to desire fewer children than negative individuals (unadjusted mean = 4.3 for positive individuals and 4.9 for negative individuals). It is important to remember that our measure for desired children is the actual number of children someone has (including current pregnancy) plus the number of additional children they wish to have in the future. This may slightly overestimate the ideal family size if participants' actual number of children exceeds their desired number.

Traditionally, Ugandans desired large families for cultural and practical reasons. This included having children to expand the clan, care for the parents in their old age and work on the family farm. While these factors still play a roll the results from our study indicate that they are of diminishing importance. By far the most commonly cited reason for stopping childbearing, in the absence of HIV/AIDS-related factors, in both the interviews and focus group discussion sessions was economic concerns, which is consistent with the literature (Wolff et al, 2000). Participants often voiced a fear that having a large family would drive them into poverty. This fear appears justified, as massive population expansion has been shown to be a major factor contributing to poverty in Uganda (Wakabi, 2006). It is now becoming socially prescribed that parents must properly educate their children and provide them with as many life chances as possible. Thus, having not enough land to distribute between their sons, lacking money to properly educate their children and/or being unable to afford treatment for them in case of illness were primary concerns leading to the cessation of childbearing. It appears that Uganda is ready to proceed through its fertility transition if these desires to limit childbearing are coupled with effective methods of fertility reduction such as family planning use. However, declining levels of infant mortality, which are not yet apparent, may also be necessary for this transition to occur.

Effect of HIV/AIDS on Fertility Desires

As discussed in the literature review, there is evidence to support two hypotheses: a HIV diagnosis decreases the desire for children and a HIV diagnosis does not alter the desire for children. All of the data obtained in this study supports the hypothesis that a HIV diagnosis decreases the desire for children amongst those who have tested for HIV. The multivariate analysis showed that HIV positive individuals were much more likely to want to stop childbearing than their HIV negative counterparts after controlling for important predictors. These results agree with those obtained in a similar study with health care users in two urban slums of Nairobi, Kenya (Baek & Rutenberg, 2005). The descriptive data from our study also supports the finding that HIV/AIDS limits the desire for children: 67% of HIV positive individuals who wished to stop childbearing mentioned their HIV status as one of the reasons for this decision, 33% reported that they would have had more children if their test result had been negative instead of positive and 51% stated that their diagnosis changed their fertility desires. Our results differed from some studies which showed that there was no difference in fertility desires between positive and negative individuals. However, most of these studies were not conducted in Uganda but rather in other sub-Saharan African countries. It is possible that Ugandans are more vigilant about taking action to reduce the spread of HIV/AIDS due to intense government campaigns and widespread awareness about the issue.

There is evidence to support the notion that those who have few or no children are much less likely to stop childbearing upon receipt of an HIV diagnosis when compared to those with more children. This is supported by the finding that for HIV positive individuals only 8% of those with two or more children wished to have additional children versus 42% of people with less than two children ($p<0.001$). Furthermore, it was mentioned in the focus group discussion sessions that those with few children are less likely to desire stopping and negative participants tended to be sympathetic towards those who have tested positive and want children if they have few or none at the time of their diagnosis. It was also found in previous studies that desire of HIV positive individuals to stop childbearing does not extend to those who have few or no children (Feldman & Maposhere, 2003, Gray et al, 1998, Grieser et al, 2001, Kline et al, 1995).

This finding makes sense given that childbearing is an extremely important facet of Ugandan culture and society. Only four HIV infected participants (all women) did not desire any children, two of whom suspected they were barren and one who had experienced twelve miscarriages and/or stillbirths. Thus, it may be more accurate to conclude that an HIV diagnosis limits childbearing but does not completely diminish the desire for children, particularly amongst those who do not yet have a child.

Reproductive Decision-Making Process

Partner discussion of fertility intentions was reported to be quite high in the semi-structured interviews: 86% of participants reported discussing either stopping childbearing or how many children they wanted to have with all of their spouses. In contrast, Woolf et al (2000) found in the Masaka and Lira Districts of Uganda that only 44% of respondents discussed whether or not to stop childbearing. One explanation for this difference may be that we interviewed HIV tested individuals whereas they sampled the general population, meaning our sample contained a larger proportion of positive participants. Our data showed that partner discussion was more common for HIV positive couples (91%) than negative individuals (81%), perhaps as there are more problems associated with pregnancy for these individuals or because they received extensive counseling regarding childbearing decisions during their VCT sessions. Although this does not account for all of the discrepancies between our findings (44% for Woolf et al. and 81% for HIV negative respondents in our study) it is also important to remember that our HIV negative participants may differ from the general population sampled by Woolf et al (2000) in that they were health care users. Furthermore, their data was obtained over ten years prior to ours and participants noted in our focus group discussion sessions that partner discussion surrounding reproductive intentions was becoming increasingly common.

Of concern is the effectiveness of partner communication surrounding reproductive desires. Comparison of responses between husband and wife couple pairs revealed that only 32% of respondents could correctly identify how many more children their partner wanted to have. Furthermore, only 78% of couples were in agreement with respect to whether or not a discussion had occurred regarding fertility intentions. Eight percent of respondents were not sure how many children their partner wanted even though they claimed to have discussed this topic. This was also found for 11% of the respondents interviewed a the study by Woolf et al (2000) in the Masaka and Lira Districts of Uganda, thus supporting the conclusion that partner communication may not always be very effective. Woolf et al (2000) also found that indirect forms of partner communication on the topic of childbearing predominated and that this often led to an overestimation of partner's desire for additional children.

Seventy-two percent of respondents reported that power over fertility decisions is split equally between themselves and their partner. Twelve percent of women reported that their spouse has greater control over reproductive decisions than they do versus only 5% of men. Woolf et al (2000) also found that men tended to be half as likely as women to report that their partner held the balance of control over reproductive decisions. However, the figure of 12% is lower than expected, as the literature supports the position that men are the primary decision makers in most sub-Saharan African countries when it comes to fertility (DeRose et al, 2002, Dodoo, 1998, Forsyth et al, 2002, Wolff et al, 2000). Social desirability bias may have contributed to the low number of individuals who admitted to lacking reproductive control in the interviews. In response to these unexpected findings we introduced a question into the focus group discussion sessions to shed light on the situation where a couple disagreed with respect to how many children they should have. All of the focus group participants who responded to this question, save one, said that the man would win under these circumstances. Thus, it appears that discussing fertility options is becoming common but that the balance of power over these decisions still remains with men. One research assistant supported this view: he felt that couples were talking about their fertility desires and women felt like they were having some input into these decisions but that their desires were still not being realized. This was also voiced by one positive female focus group participant who became pregnant following her diagnosis when she stated that "if you tell the man that lets have maybe three children whom we can manage to look after he tells you he still wants to have more and as a woman you are weakening but the man does not weaken". Thus, women may be likely to give in to their partners' wishes with respect to childbearing whereas men remain steadfast. Woolf et al (2000) also found that although partner discussion occurred it tended to be one-sided, favouring the husband.

Family Planning Use

According to the 2000/2001 DHS, 22.8% of the population was currently using contraception and 44.1% were ever users (Anonymous, 2004). In contrast, we found that 42% of respondents were currently using family planning and 65% of respondents had used it at some point in their lifetime. This difference can be reconciled in a many ways. Firstly, our sample included HIV tested individuals who are more likely to be contraceptive users than the general population who were sampled in the DHS survey. As well, our participants included a much larger proportion of HIV positive individuals who have been shown in our study as well as others to be more likely to be users of family planning (Hunter et al, 2003). Furthermore, their study was conducted seven years prior to ours and contraceptive prevalence has been shown to be increasing in Uganda (Anonymous, 2004).

When only individuals currently at risk of pregnancy are included in the analysis it was found that 69% were currently using contraception. HIV positive respondents (79%) were still much more likely to be currently using contraception than HIV negative respondents (40%) even when only those at risk of pregnancy were included in the analysis and this result was highly statistically significant ($p<0.001$). However, positive and negative individuals were also found to differ greatly on the methods of contraception they used. Male condoms were by far the most commonly utilized contraceptive method by HIV positive individuals; 77% of those currently using family planning chose condoms. Other studies have also found that HIV positive women have more positive attitudes towards condoms and are more likely to use them than HIV negative women (Rutenberg & Baek, 2005). It is possible that reports of condom use were inflated due to social desirability bias as the vast majority of the HIV positive participants would have been counseled regarding the importance of condom use and may have been hesitant to admit nonuse.

When only highly effective methods of pregnancy prevention (hormonal methods, sterilization and abstinence) were considered it was found that only 21% of individuals at risk of pregnancy were currently using an effective method. HIV positive participants at risk of pregnancy were found to actually be less likely to be using a highly effective method of family planning than negative participants, although the result was non-significant (19% versus 27%, p=0.168). This is problematic because although condoms are beneficial for reducing HIV transmission they are only 86-90% effective for pregnancy prevention with one year of typical use (World Health Organization, 2000). While effectiveness increases with perfect use the mechanics of use as well as problems associated with expiry dates and achieving proper storage conditions in tropical locations make this difficult to achieve. Thus, those who rely solely upon condoms long term are putting themselves at risk of unwanted pregnancy. As our research participants were all married or cohabiting, it is likely that they are having regular sexual contact and will be doing so for many years. Condom use alone is not necessarily the best option for these individuals, particularly those who are HIV positive and strongly wish to stop childbearing.

The best course of action for infected individuals is to use dual protection in the form of condoms for prevention of HIV transmission coupled with a highly effective contraceptive such as OC pills, injections, Norplant, IUD or sterilization. We found that only eight participants (seven of whom were HIV infected) were using dual protection. This low level of acceptance is supported by other studies which have shown that many rural Ugandans do not understand the concept of dual protection and question its relevance (Chacko, 2004). It is important for health providers to promote dual protection amongst their clients. Our data suggests that health workers counsel HIV positive couples to use condoms and only resort to another method if they experience problems. This has resulted, at least in one case, in an HIV positive participant switching from a more effective hormonal method of birth control to the male condom.

Rather, this patient could have been counseled to use condoms in addition to the hormonal method to further reduce the risk of pregnancy. Dual method use should always be advised for those who are infected or at risk of HIV infection and condoms alone should not be seen as sufficient protection, particularly for those couples that are comfortable using other methods. Because condom use has been taken up by many of the HIV positive patients who were interviewed, usually on the basis of heath workers' advice, it is conceivable that dual protection use could drastically increase if providers were advising this strategy to their clients.

We found that three respondents were using contraception without their husband's knowledge. This represents three percent of female contraceptive users. Other studies have show covert contraceptive to be more common and to account for between six and twenty percent of all contraceptive use in sub-Saharan Africa (Biddlecom & Fapohunda, 1998). When removing participants who were using male condoms, which require the consent of the husband, from our analysis the percentage of covert contraceptive use increases to eleven percent.

We found the unmet need for family planning to be 19%. This figure represents the percentage of individuals at risk of pregnancy who did not want more children and were not using contraception. However, this value may be on the low end it does not include participants who require family planning for birth spacing. Twenty-three percent of participants reported wanting to use family planning and not being able to, which is another indicator of unmet need. These figures are lower than most estimates which report that the unmet need in Uganda is up to 60% (Anonymous, 2004, Blacker et al, 2005, Lutalo et al, 2000). As our participants are health care users we would expect to find the unmet need to be lower than in the general population. Furthermore, we found that 78% of participants had a need for a more highly effective method of contraception as most were relying upon male condom use alone in long term relationships. We also found that only one of thirteen pregnancies in HIV positive women was planned, which indicates that these participants had difficulty turning their desire to stop childbearing into a reality. The most often cited reason for these unwanted pregnancies was fear of side effects of contraception.

By far the most commonly mentioned barrier to family planning use is fear of side effects. This agrees with the literature as concern regarding side effects was by far the most commonly cited reason for nonuse of contraception amongst 15-29 year old married women who do not intend to use contraception in the future (Anonymous, 2004). It has also been identified as a major barrier to family planning use in many other studies conducted in sub-Saharan Africa (Baek & Rutenberg, 2005, Bongaarts & Bruce, 1995). Only one focus group respondent mentioned being counseled about side effects. She was told that they are normal for the first few months and usually subside so it is important to continue on with the method for this time if the side effects are not serious. This type of advice needs to be given to all patients who wish to limit or space births. Furthermore, there are simple methods to reduce side effects, such as taking oral contraceptive pills in the evening rather than the morning, which can be included in family planning counseling sessions. As well, patients can be counseled that amenorrhea is a side effect but that it does not harm the woman and that it does not reduce her ability to conceive in the future. Providers need to do more to address fears of side effects by making sure patients are informed of what to expect and how to handle these issues when they arise. This can reduce the experience or perceived experience of side effects for these patients which will improve their quality of life. It can also lead to greater acceptance of family planning in the community because many women do not use contraception based upon rumors of side effects rather than personal experience.

Although not commonly mentioned as a barrier to family planning use it was noted that only a few methods were readily available to participants. Only OC pills, injectables and condoms are available in the shops and local health centres, leaving few options for women who experience side effects with use of hormonal methods. IUDs and sterilization are uncommon, perhaps because these procedures must be performed by a physician which would necessitate a hospital visit. However, health workers should promote these methods to couples who wish to stop childbearing permanently, particularly if they are HIV positive (IUD use is safe for most HIV positive women). The permanence of these methods should be stressed in order to convince patients that the expense of a hospital visit is justified as it will them save money in the long run.

Misconceptions about family planning also need to be addressed. Many participants were found to believe serious side effects to be ubiquitous rather than uncommon occurrences with family planning use. Furthermore, rumors exist that problems such as cancer and infertility can result from family planning use. These misconceptions must be quelled. Efforts that include health workers, local politicians/community leaders and peers who have used family planning successfully should be utilized in order to lay these dangerous rumors to rest. National leaders and spokespeople should also be involved as evidence from the HIV/AIDS epidemic shows how strong a campaign of this magnitude could be. The political commitment and support given to HIV/AIDS is lacking with respect to the related issue of family planning (Blacker et al, 2005). President Museveni has publicly stated on many occasions that he believes Uganda's population is its best resource. Thus, his support for family planning is weak because he himself does not want to limit the population of the country. Altering this standpoint would be instrumental in reducing the stigma and misconceptions associated with family planning and increasing its acceptance.

This type of campaign would also be useful in reducing partner opposition to family planning, which was also shown to be a barrier to use. Other studies conducted in Uganda have also show partner opposition to be a challenge (Kaida et al, 2005, Wolff et al, 2000). Woolf et al (2000) found that partner opposition caused a significant increase in unmet need for contraception reported by women and to shift the proportion of methods used towards a greater use of traditional rather than modern methods. Partner opposition to family planning was shown to account for 15% of the unmet need (Wolff et al, 2000). Male involvement in family planning, including couples counseling, is generally believed to be the main means by which to reduce partner opposition. Couples counseling is done whenever possible at the Rwimi Health Centre, however problems arise when men cannot be counseled because they do not seek medical care and thus do not visit the health unit.

Although few participants noted their lack of knowledge about or access to family planning as factor limiting use they did mention these as barriers for others in their villages. This makes sense, since our participants were health care users. Some participants, including health workers, mentioned community outreach as a means by which to increase the contraceptive prevalence in the region. A few people mentioned that this had been done before but the DHS showed that very few Ugandans obtained their contraceptives from outreach workers or community based distributors (Anonymous, 2004). It is not clear if this is due to inadequate services or a lack of uptake. This is an area that could be explored in the future studies.

HIV Testing

We found that women were much more likely to test for HIV than men. This was apparent during recruitment, as it was difficult to come up with a list of enough men who tested negative to fulfill the sample size requirements. It was also mentioned as a challenge by some participants, including most of the health care workers. They noted that women were the ones who came for testing but that they do not make the decisions about childbearing and family planning. Thus, not having men involved in testing was limiting interventions from occurring following an HIV diagnosis. Health providers called for the use of every method possible to increase male participation in HIV testing. They suggested involvement of community leaders and politicians. Some of the negative men who participated in the focus groups requested that testing services be decentralized to the villages so that transport costs and stigma would not be deterrents to testing.

Increasing the number of men who test for HIV is important for two reasons. First, it is impossible for people to alter fertility intentions based upon serostatus if they do not test. Studies have shown that simply knowing that there are many people infected in their region is not enough incentive to limit childbearing (Rutenberg et al, 2000).

Instead, a positive HIV test result or experience of AIDS-related signs/symptoms is generally required before an individual considers altering their fertility due to HIV/AIDS. Therefore, if people are testing in low numbers then the impact of change in fertility will be minimal on a large scale even if serostatus does have a marked impact on the RDM process of individuals. We included only tested individuals in our sample and also asked the participants if they experienced AIDS related symptoms or illness so we could control for this in the multivariate model. However, experience of AIDS related symptoms or illness was not significant after accounting for other factors. The second reason it is important to increase the number of men who test for HIV is that men tend to be key decision-makers with respect to fertility and family planning. Women knowing their status it is not necessarily enough to reduce fertility in the face of HIV/AIDS: HIV infected women likely require the consent of their partner to limit childbearing following a diagnosis.

Women tend to test more for HIV because they have greater contact with the health system when they access maternal and child health services. Men were reported to fear testing because they think that knowing their status will make them sicker since they would be constantly worrying about it. Both sexes were said to avoid testing because it could result in blame as to who introduced the disease into the relationship, often leading to divorce. This was mentioned many times in the focus group discussion sessions as a reason why people do not disclose their status to their partner. Non-disclosure of serostatus was reported to be common in the focus group discussion sessions and has been described in other studies (Nebie et al, 2001). However, our interview results suggest that non-disclosure of serostatus to the partner is rare. We found only seven HIV positive participants (3.5%) who did not disclose their test results to all of their spouses. Since disclosure of results is generally a prerequisite for the alteration of fertility following a diagnosis it would have been a problem if we had found that many participants were not disclosing their status to their partner. However, we did not find this to be the case with our sample. It is likely that counseling by health workers lead to this high rate of status disclosure; during the post-test counseling session clients are directed to discuss their results with their partner. If they are afraid to do this alone they are advised to bring their spouse to the health centre to meet with the health worker so that the results can be discussed in the presence of a health provider.

Knowledge – Strengths and Gaps

Our study assessed participant's knowledge of MTCT and, to a lesser extent, family planning. We evaluated knowledge regarding MTCT because it has been shown that lack of understanding regarding MTCT reduces desire to stop childbearing upon receipt of an HIV diagnosis (Murphy et al, 1998). We did not find that knowledge regarding MTCT was a factor which influenced the desire to stop childbearing after controlling for other variables. Our findings, however, are still of interest in describing the participants' knowledge regarding this issue.

Overall, 97% of respondents believed that HIV could be transmitted from mother to child during pregnancy and/or delivery. These results agree fairly well with the 2000/2001 DHS which found that 83% of Ugandans surveyed knew that HIV can be transmitted from mother to child (Anonymous, 2004). Our results are predictably higher since we interviewed health care users rather than the general public.

Most participants believed that if the mother is on ARVs and/or delivers in the hospital then the risk of MTCT is reduced significantly. On average, the impact of hospital delivery was deemed to be more effective at reducing transmission than ARVs. It is possible that participants were associating hospital delivery with PMTCT or Nevirapine treatment even though the drug can be given in advance and the mother can take it at home before she delivers in the village. Hospital delivery did not imply that a cesarean section was performed as elective cesarean is uncommon, even for those who are HIV infected, and the expertise and supplies necessary to perform this procedure are not available in the local health centres. Rather, interventions such as the use of gloves, clamping the cord immediately to reduce blood flow from mother to child and placing the child on the abdomen of the mother immediately to reduce the infant's contact with the mother's bodily fluids are employed when delivery occurs in a health setting. That ART, Nevirapine and cesarean delivery significantly reduce the risk of MTCT has been frequently demonstrated (Hogan & Salomon J. A., 2005, Jackson et al, 2003, Kourtis, 2002). The literature does not address the other hospital-based interventions, thus it is not possible to determine if they significantly reduce the incidence of MTCT. Beliefs of zero risk of MTCT when positive individuals deliver in a health centre are likely purported by health workers who themselves believe this to be the truth. It is beneficial to encourage positive clients to deliver in a clinic or hospital to reduce the chance of infection, increase the chances that interventions can be performed in the case of obstetric emergency and ensure that Nevirapine is administered, if necessary. However, rumors of zero risk of MTCT when delivery occurs in a health setting are problematic as individuals need to be fully aware of the risks associated with conceiving when positive and take these into consideration when making reproductive decisions.

It was found that the chance of MTCT tended to be overestimated in the absence of ART and hospital delivery and overestimated when these interventions are employed. Other studies have also shown similar findings (Grieser et al, 2001). We found that only 12% of participants thought that it was possible for MTCT to occur if the mother was on ART and delivered in a health setting. This is problematic, as even with elective cesarean section, ART and without breastfeeding there is still a small chance of MTCT (Hogan & Salomon J. A., 2005, Jackson et al, 2003, Kourtis, 2002). Furthermore, our results, and those from other studies, show that most Ugandans cannot afford breast milk substitutes and that even when they can the lack of clean water to prepare formula often makes this option undesirable (Jackson et al, 2003). Thus, even if a child is not infected in utero or at birth they still are at risk of MTCT through breastfeeding.

We found that the majority (60%) of respondents understood that the risk of MTCT is not absolute. This contrasts with other studies that have shown participants to believe that the risk is either 100% or 0% (Grieser et al, 2001). We also did not find any evidence to support previous reports that HIV positive women were believed not to be able to become pregnant (Kipp et al, 2002). Our findings may reflect the intensive counseling these clients have received regarding MTCT.

We found that knowledge of the existence of family planning methods was quite high amongst the study participants. This agrees with other literature (Anonymous, 2004, Kiapi-Iwa & Hart, 2004). Lack of knowledge was sometimes reported with respect to others in the village who do not visit the health centre, however this cannot be confirmed. Overall it appears that lack of awareness of family planning is not a major issue in the study area. On the other hand, stigma and misconceptions with respect to family planning are rampant. Rumors that condoms cause cancer, oral contraceptives damage the uterus, hormonal methods make farming impossible and contraception causes fetal abnormalities were commonly reported. Until these rumors are quashed it seems that family planning use will be limited in the region.

Service Provision

A Population Council study conducted with health care users in Kenya showed that only 50% of HIV positive women and 42% of negative women had discussed family planning with their provider (Baek & Rutenberg, 2005). In contrast, we found that 82% of respondents reported that family planning was discussed during their VCT session. HIV positive individuals and men were more likely to reported being counseled on this topic than HIV negative individuals and women. Most respondents reported being counseled about multiple contraceptive methods rather than only about condoms.

Furthermore, 77% of respondents reported that MTCT was discussed during their VCT session. Positive individuals were more likely than negative ones to have discussed this topic during their counseling session. Our qualitative analysis showed that many respondents reported being counseled to limit or stop childbearing following an HIV diagnosis. The vast majority of participants in the Population Council study in Kenya also reported receiving directive counseling from health workers regarding stopping childbearing or birth spacing if HIV positive (Baek & Rutenberg, 2005). In both our study and theirs the participants appeared to take up this advice, as shown by the use of similar language between participants and health workers when describing why their diagnosis made them want to stop childbearing (Baek & Rutenberg, 2005). The Population Council study also showed that health providers had an instrumental impact in influencing women's decision-making regarding family planning (Baek & Rutenberg, 2005). This result agrees with our findings: we found that many respondents seemed to take the advice of health workers without questioning. In contrast, a study conducted in Cote D'Ivoire found that counseling did not lead to uptake of contraceptives or protection of sexual intercourse following an HIV diagnosis (Desgrees-du-Lou et al, 2001). Directive counseling may reduce the number of pregnancies in HIV positive women but care needs to be taken to ensure that it does infringe upon their human rights. The policy of the Ugandan government and the proclamations of the ICPD agree that patients should be provided with information to make reproductive decisions but do not receive advice in order to allow autonomy and avoid blame with respect to these decisions. However, it appears that advice is being given regardless of these policies.

All of our results with respect to health services indicate that VCT and family planning services are quite well integrated. This was surprising, given criticism that these programs tend to be implemented and funded vertically by different agencies (Lush, 2002, United Nations, 1994). That we interviewed clients attending public health centres may have made a difference: the government clinics must provide all services whereas privately funded organizations can decide which services they wish to offer. For example, the Catholic hospital in Fort Portal does not provide condoms to clients as this would violate the beliefs of the Catholic Church. Our results that service integration is occurring are very positive as there is evidence to support that PMTCT programs are more effective at promoting contraception use amongst clients if the family planning services are integrated into the PMTCT program rather than being offered as a parallel service (Rutenberg & Baek, 2004).

Stigma and Discrimination

All of the HIV positive women who became pregnant following their diagnosis reported disclosing their status to health workers if they came into contact with them during their pregnancy. This result agrees with those obtained by Pool et al. (Pool et al, 2001) in their study conducted in south-west Uganda. Furthermore, all of the data suggests that HCWs do not discriminate against HIV positive women who become pregnant following their diagnosis. This was shown in both the qualitative and quantitative portions of the study: the only time different treatment of positive and negative clients by HCWs was reported it was in terms of benefits given to positive women rather than discriminatory behaviour. It was reported that health workers often advise HIV positive women to stop childbearing, however it seems that they do not treat clients poorly if they do not follow their advice. The lack of discrimination by health workers is commendable and somewhat unexpected considering reports of stigma and discrimination experienced by HIV positive pregnant woman at the hands of health workers in the literature (Feldman & Maposhere, 2003, Sherr et al, 2003).

The situation is somewhat different when the community members are considered. The quantitative study component showed that only seven percent of the participants felt it was okay for HIV positive women to be come pregnant under any of the circumstances described. The focus group discussion data also showed that many participants felt that HIV positive people who knowingly became pregnant despite understanding the risks were illiterate or unreasonable. However, there were also quite a few focus group participants who felt that HIV positive woman could become pregnant under certain circumstances or if they took certain precautions to reduce MTCT. The HIV positive women who became pregnant following their diagnosis reported experiencing a negative reaction from some community members, such being laughed at or having their decision questioned. However, the participants were not too disturbed by this treatment and no threatening or abusive remarks were reported. Overall, there seemed to be disapproval from the community when HIV positive woman choose to become pregnant but outright discrimination appears to be minimal.

Chapter 5: Conclusions and Recommendations

5.1 Key Findings

- Those who have tested HIV positive are more likely to want to stop childbearing than those who have tested HIV negative
- HIV status is a major factor taken into account when making reproductive decisions
- HIV positive individuals are more likely than negative individuals use contraception, however this difference is mostly due to high levels of male condom use by HIV positive individuals
- The unmet need for contraception was found to be in the range of 19-23%
- Use of family planning methods that require physician input is low (such as sterilization and IUDs)
- Use of highly effective methods of family planning is extremely low amongst both HIV positive and negative individuals at risk for pregnancy
- Use of dual protection (condoms plus another method) is very uncommon
- Fear of side effects and stigma/misconceptions are major factors that limit family planning use
- Women often lack control over reproductive decisions, including how many children to have and whether or not to use family planning. This is mainly due to their lack of economic power.
- Partner discussion of reproductive desires is common but not always effective
- Many misconceptions exist surrounding family planning and HIV/AIDS:
    - Condoms cause cancer
    - Oral contraceptive pills cause problems with the uterus
    - MTCT is not possible if delivery occurs in a health setting, if mother receives PMTCT services and/or if mother is on ART
    - People taking hormonal contraceptives cannot work as farmers as they are weak, ill, dizzy, have headache and/or bleed continuously
    - Family planning methods can cause miscarriage, abortion, fetal abnormalities and deformed children

5.2 Recommendations

- Health workers should continue to provide information regarding the risks of childbearing when HIV positive to all positive and at risk clients
- Myths regarding MTCT need to be addressed, including informing HIV positive clients that it is still possible for their child to be infected even if they deliver at the health centre, are on ART and/or receive PMTCT services
- Integration of HIV/AIDS and family planning services needs to be continued at local health centres
- Clients should be counseled to use dual protection (condoms and another hormonal/permanent method) in order to avoid pregnancy and HIV transmission rather than being counseled to use condoms alone. This is particularly important for HIV positive individuals and those HIV negative individuals at risk of HIV infection and/or pregnancy.
- Counseling of family planning should address side effects including describing common side effects, discussing simple methods of avoiding side effects (such as taking pills at night rather than in the morning) or dealing with them (such as using artificial lubrication if vaginal secretions decrease). Clients should be advised as to which side effects are problematic so they know when to seek medical attention – peer support and testimonials from satisfied users could also be utilized as a method of reducing fear of side effects of family planning
- Measures should be taken to promote long term family planning methods that are not available in the local health centres such as sterilization and IUDs
- Stigma and misconceptions associated with family planning need to be addressed at all levels and by multiple sectors
- All means need to be exploited to increase the number of people (particularly men) who test for HIV – this can include radio campaigns and involvement of local and district level politicians
- Programs that increase women's educational attainment and/or earning power could contribute positively to reducing unwanted pregnancies by increasing women's power in their relationship thus allowing them to be involved in decisions regarding fertility, family planning and sexual health

5.3 Study Strengths

The main strength of the study is the use of both qualitative and quantitative methods to address the research questions. Qualitative responses were often obtained with the semi-structured interview questionnaire to ensure that the full meaning of the participants' response was captured and to allow unusual responses to be reevaluated. As well the topics from the questionnaire were further explored and evaluated in the focus group discussion sessions, allowing for triangulation of results and further explanation of quantitative trends. Furthermore, it permitted the researchers to more accurately determine the motives or outside forces which lead to certain responses given to the quantitative questions. Thus, in depth information was obtained regarding trends that did not make logical sense and topics that emerged but were not properly addressed by the semi-structured interview questionnaire.

Another asset was the large sample size obtained for the quantitative portion of the study. This allowed for sufficient power to scientifically detect the differences that were apparent based upon personal observation (could detect differences as small as 15% between the HIV positive and negative groups and the actual difference between these groups was 39%).

The assistance provided by local health professionals, community volunteers and research assistants also significantly increased the quality of this study. These individuals understood the cultural and social context in which the responses were given and were often able to shed light on important issues. This resulted in many improvements to the questionnaire, enhanced organization and logistics of the project and a more meaningful and accurate interpretation of the results of the study. The benefits of local participation in this venture cannot be overstated.

5.4 Study Limitations

The main concern for the quantitative portion of the study was the comparability between the HIV positive and HIV negative groups. Since the HIV negative participants were all recruited from the Rwimi Health Centre whereas the HIV positive participants were drawn from Rwimi, Bigodi and Kibiito Health Centres there is a possibility that significant differences will exist between these two groups. Socio-demographic information was obtained so that many of these differences could be controlled, however it is possible that factors not considered also had an effect. As the population is fairly homogenous and the recruitment sites all mainly catered to rural patients it is our hope that the use of multiple sites for the HIV positive population did not lead to erroneous findings.

Some potentially important factors which might predict desire to stop childbearing in HIV positive individuals were not assessed. For example, the length of time since the HIV diagnosis might be an important predictor of desire to stop childbearing but was not included in the questionnaire. Those who did become pregnant following their HIV diagnosis tended to have known their status for a long time. There are many ways in which the time elapsed following diagnosis can influence the decision to have children. For example, people may initially decide to stop childbearing after finding out they are positive but then change their mind if they remain asymptomatic for a long time or if their health improves while receiving ART. This information may have been informative and would have been included were it considered at the onset of the study. However, the strength of the relationship between HIV status and desire to stop childbearing was great which suggests that the finding would hold true even if more predictors were included in the model.

It was not ideal to interview the HIV negative respondents immediately after receiving their HIV test results as they may have felt anxious or worried about their results and the interview process could have contributed to these negative feelings. However, it was very difficult to locate participants who tested at Rwimi Health Centre in the field, and it would have been almost impossible to locate HIV negative clients in this manner, as they were not well known to the health centre staff and the CB-ARV project volunteers. Thus, we felt it was necessary to interview the HIV negative participants at the clinic after receiving their results in order to ensure the study could be completed within the allocated time-frame and budget.

The data is not representative of the general population as individuals who test for HIV differ from those who do not. Thus, the data is not generalizable to the general population of the region but is rather specifically indicative of those who have tested for HIV. In reality the data might more accurately depict the views of health care users than non-users because those who test for HIV might tend to be more familiar and more comfortable with accessing health services than those who do not test. However, those who test might also differ from the general population in terms of risk factors for HIV. It is important to remember who the data represents when interpreting the results. For example, 79% of HIV positive individuals ever having used contraception sounds impressive until one takes into account the many people in the community who have not tested and are also unlikely to be using family planning as they have little contact with the health system. Contraceptive use rates are almost surely higher for this tested population than for the general population.

Participation bias was not a factor at the Bigodi and Kibiito and Rwimi Clinic (post-test) recruitment as the participation rate for these locations was above 90%. This is likely because the Bigodi Health Centre refers individuals who test positive to the Bigodi Post-Test Club and, thus, these individuals were usually known by the club leader who was our community volunteer in this area. In Kibiito all of the individuals who were eligible were on the ARV program and were thus known to the health care system and the staff member of the Kibiito Health Centre who aided the research team with recruitment.

Problems with participant recruitment occurred when attempting to find those who tested for HIV at Rwimi Health Centre in the field. Only 52% of those identified were recruited into the study. However, very few individuals refused to participate in the study, with 1.5% refusing outright and 6.9% not showing up to the health centre after a flyer was delivered to their house. It was much more common for people to refuse to participate if they were recruited post-test from the Rwimi Health Centre than for those recruited in the field, likely because VCT patients spend all day at the clinic undergoing counselling sessions, blood testing and waiting for their test results. Many of these individuals cited being tired or hungry as their reasons for not participating in the study. Furthermore, as they were all HIV negative there may have been less perceived importance or benefits to be obtained from the study by these individuals when compared to those who are HIV positive. The main problem encountered with participant recruitment was that in Rwimi many people could not be located in the villages. There are many possible reasons for this. Firstly, some health workers suspect many people give an incomplete or false name and/or address when they come to the clinic for HIV testing because they are concerned about protecting their confidentiality. Secondly, in larger villages or trading centres it is not possible for the LC1 chairperson and/or community volunteer to know every individual in their village. Those living in trading centres tend to be mobile and were sometimes reported to have moved to a different area. Another barrier is the use of nicknames: many women are known by their husband's name, son's name or pet name thus making them difficult to locate. It is not possible to know if those who could not be located differed significantly from those who participated in the study. As those recruited from the field in Rwimi were more likely to be HIV positive and male it is possible that participation bias affected the results of the univariate and multivariate analysis results.

Interviewer bias may have occurred since the research assistants may have had preconceived ideas about how participants should respond and about how to interpret vague responses. Although this bias could not be completely overcome it was be minimized by employing research associates who are well-trained and experienced in administering the questionnaire and by pre-testing the questionnaire. It is also possible that the use of four different interviewers may have led to bias if they interpreted questions or coded responses in a different manner. This was controlled by discussing each question and response in detail during the training sessions as well as conducting group debriefing sessions daily whereby questions from the interviewers were encouraged and the best course of action to take was determined as a group.

Social desirability bias was the most important bias that was likely encountered, as participants may have attempted to tell the interviewer what they thought they wanted to hear or what was socially acceptable rather than the absolute truth. One particular case where this likely occurred was in the reporting of HIV test result disclosure to the partner: 96% of HIV positive respondents reported disclosing their serostatus to their partner. This is unexpectedly high based upon other literature and the qualitative findings from our study. Since study participants would have been encouraged to tell their partner their results during their post-test HIV counseling it is conceivable they would be hesitant to admit to the non-disclosure in the interview. Social desirability bias is common and impossible to eliminate in self-report studies that deal with sensitive subject matter. Comparisons between interview and focus group data were used to attempt to determine the extent to which this was occurring and to better understand the reality of certain issues. In the discussion section these congruencies and discrepancies between the qualitative and quantitative data were mentioned and analyzed.

5.5 Future Directions

This study quite effectively captured the difference in fertility desires between HIV positive and HIV negative individuals. However, it also identified various barriers to achieving fertility desires. These include fear of side effects of contraception and low numbers of men testing for HIV/AIDS, as well as other factors. In order to determine if a desire to reduce childbearing amongst HIV positive individuals actually results in a lower fertility rate amongst this population further research is needed. We would propose a follow up study in the same location, possibly also with the same participants, to be carried out in two to three years time. This study would identify incident pregnancies that occurred during the follow up period. Achievement or avoidance of an incident pregnancy could then be compared with the fertility desires of the client that were reported during this initial study. Reasons for not achieving fertility desires could be assessed and the true impact of an HIV diagnosis on fertility could be determined. This study would capture in a more comprehensive way the impact of HIV/AIDS on reproductive decision-making and childbearing. Our study was important in showing that HIV/AIDS reportedly reduces fertility above and beyond the biological limitations of HIV positive individuals by affecting reproductive decisions. However, making the decision to have fewer children means little if this desire cannot be realized.

As many study participants mentioned the need for decentralization of HIV/AIDS and family planning services to the smaller village communities this is another area that could be examined. Studies that assess the acceptability and plausibility of these programs and/or that pilot test these services could be of utmost importance in increasing contraceptive prevalence and HIV testing in the region.

5.6 Conclusions

Prior studies have shown that HIV positive women have lower fertility, however they have largely been unable to tease apart the causal factors because HIV infected women have reduced fertility for biological reasons (Gray et al, 1998, Ross et al, 2004). We have shown that individuals who test HIV positive in the Kabarole region of Uganda are more likely to want to stop childbearing than those who test HIV negative. This relationship is strong and was found to exist in the descriptive statistical data, multivariate analysis and qualitative data. It appears that those with many children wish to stop childbearing on receipt of an HIV diagnosis whereas those who have few or no children wish to either stop or limit childbearing. This is an important finding because it can lead to a reduction in the number of pregnancies in HIV positive women, thereby reducing the number of HIV infected children.

It is also important to note that we found that many barriers exist for individuals in this region with respect to realizing their fertility desires. These include lack of power of women to make reproductive decisions, stigma and misconceptions regarding family planning, misunderstandings regarding the risk of MTCT under various conditions and fear of side effects of family planning methods. Until these barriers are addressed it is possible that those who test positive will not be able to reduce their fertility in response to receiving an HIV diagnosis. If this happens, benefits that could be achieved through reduction of fertility by HIV positive individuals will not be attained.

References

Uganda 2000-2001: Results from the demographic and health survey. (2004) *Stud Fam Plann* **35**: 70-74

Allen S, Serufilira A, Gruber V, Kegeles S, Van de Perre P, Carael M, & Coates TJ (1993) Pregnancy and contraception use among urban Rwandan women after HIV testing and counseling. *Am J Public Health* **83**: 705-710

Baek C & Rutenberg N (2005) *Addressing the family planning needs of HIV-positive PMTCT clients: Baseline findings from an operations research study.* Population Council: Washington, DC.

Bankole A, Rodriguez G, & Westoff CF (1996) Mass media messages and reproductive behaviour in Nigeria. *J Biosoc Sci* **28**: 227-239

Baylies C (2000) The impact of HIV on family size preference in Zambia. *Reprod Health Matters* **8**: 77-86.

Biddlecom AE & Fapohunda BM (1998) Covert contraceptive use: prevalence, motivations, and consequences. *Stud Fam Plann* **29**: 360-372

Blacker J, Opiyo C, Jasseh M, Sloggett A, & Ssekamatte-Ssebuliba J (2005) Fertility in Kenya and Uganda: a comparative study of trends and determinants. *Population Studies* **59**: 355-373

Bongaarts J & Bruce J (1995) The causes of unmet need for contraception and the social context of services. *Studies in Family Planning* **26**: 57-75

Brocklehurst P & French R (1998) The association between maternal HIV infection and perinatal outcome: a systematic review of the literature and meta-analysis. *British Journal of Obstetrics & Gynaecology* **105**: 836-848

Chacko S (2004) *Investigating Adolescent Perceptions of HIV and Pregnancy, Fort Portal, Uganda, Africa*. University of Alberta, Edmonton, Canada.

DeRose LF, Dodoo Nii-Amoo F., & Patil V (2002) Fertility desires and perceptions of power in reproductive conflict in Ghana. *Gender & Society* **16**: 53-73

Desgrees-du-Lou A, Msellati P, Viho I, Yao A, Yapi D, Kassi P, Welffens-Ekra C, Mandelbrot L, Dabis F, & ANRS 049 Ditrame Study Group (2001) Incidence of pregnancies among African HIV-infected women, Abidjan, 1995-2000. *AIDS* **15**: 2327-2330

Dodoo FN (1998) Men matter: additive and interactive gendered preferences and reproductive behavior in Kenya. *Demography* **35**: 229-242

Ezeh AC (1993) The influence of spouses over each other's contraceptive attitudes in Ghana. *Stud Fam Plann* **24**: 163-174

Fabiani M, Nattabi B, Ayella EO, Ogwang M, & Declich S (2006) Differences in fertility by HIV serostatus and adjusted HIV prevalence data from an antenatal clinic in northern Uganda. *Tropical Medicine and International Health* **11**: 182-187

Feldman R & Maposhere C (2003) Safer sex and reproductive choice: findings from "positive women: voices and choices" in Zimbabwe. *Reprod Health Matters* **11**: 162-173

Fitaw Y, Berhane Y, & Worku A (2004) Impact of child mortality and fertility preferences on fertility status in rural Ethiopia. *East Afr Med J* **81**: 300-306

Forsyth AD, Coates TJ, Grinstead OA, Sangiwa G, Balmer D, Kamenga MC, & Gregorich SE (2002) HIV infection and pregnancy status among adults attending voluntary counseling and testing in 2 developing countries. *Am J Public Health* **92**: 1795-1800

Foster CJ & Lyall EG (2006) HIV in pregnancy: evolution of clinical practice in the UK. *Int J STD AIDS* **17**: 660-667

French R & Brocklehurst P (1998) The effect of pregnancy on survival in women infected with HIV: a systematic review of the literature and meta-analysis. *British Journal of Obstetrics & Gynaecology* **105**: 827-835

Gray RH, Wawer MJ, Serwadda D, Sewankambo N, Li C, Wabwire-Mangen F, Paxton L, Kiwanuka N, Kigozi G, Konde-Lule J, Quinn TC, Gaydos CA, & McNairn D (1998) Population-based study of fertility in women with HIV-1 infection in Uganda. *Lancet* **351**: 98-103

Gregson S, Zhuwau T, Anderson RM, & Chandiwana SK (1998) Is there evidence for behaviour change in response to AIDS in rural Zimbabwe? *Soc Sci Med* **46**: 321-330

Grieser M, Gittelsohn J, Shankar AV, Koppenhaver T, Legrand TK, Marindo R, Mavhu WM, & Hill K (2001) Reproductive decision making and the HIV/AIDS epidemic in Zimbabwe. *Journal of Southern African Studies* **27**: 225-243

Gyimah SO & Fernando R (2002) The effects of infant deaths on the risk of subsequent birth: a comparative analysis of DHS data from Ghana and Kenya. *Soc Biol* **49**: 44-57

Hagewen K & Morgan S (2005) Intended and ideal family size in the United States, 1970–2002. *Population and Development Review* **31**: 507-527

Hogan DR & Salomon J. A. (2005) Prevention and treatment of human immunodeficiency virus/acquired immunodeficiency syndrome in resource-limited settings. *Bulletin of the World Health Organization* **83**: 135-143

Hunter SC, Isingo R, Boerma JT, Urassa M, Mwaluko GM, & Zaba B (2003) The association between HIV and fertility in a cohort study in rural Tanzania. *J Biosoc Sci* **35**: 189-199

Igwegbe AO & Ilika AL (2005) Knowledge and perceptions of HIV/AIDS and mother to child transmission among antenatal mothers at Nnamdi Azikiwe University Teaching hospital, Nnewi. *Nigerian Journal of Clinical Practice* **8**: 97-101

Jackson JB, Musoke P, Fleming T, Guay LA, Bagenda D, Allen M, Nakabiito C, Sherman J, Bakaki P, Owor M, Ducar C, Deseyve M, Mwatha A, Emel L, Duefield C, Mirochnick M, Fowler MG, Mofenson L, Miotti P, Gigliotti M et al (2003) Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: 18-month follow-up of the HIVNET 012 randomised trial. *Lancet* **362**: 859-868

Kaida A, Kipp W, Hessel P, & Konde-Lule J (2005) Male participation in family planning: results from a qualitative study in Mpigi District, Uganda. *J Biosoc Sci* **37**: 269-286

Kiapi-Iwa L & Hart GJ (2004) The sexual and reproductive health of young people in Adjumani district, Uganda: qualitative study of the role of formal, informal and traditional health providers. *AIDS Care* **16**: 339-347

Kilian A (2002) *HIV/AIDS control in Kabarole District, Uganda*. Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ)

Kimani M (2001) Behavioural effects of infant and child mortality on fertility in Kenya. *Afr J Reprod Health* **5**: 63-72

Kipp W (2006) Personal communication

Kipp W, Kabagambe G, & Konde-Lule J (2002) HIV counselling and testing in rural Uganda: communities' attitudes and perceptions towards an HIV counselling and testing programme. *AIDS Care* **14**: 699-706

Kipp W, Kabagambe G, & Konde-Lule J (2001) Low impact of a community-wide HIV testing and counseling program on sexual behavior in rural Uganda. *AIDS Education and Prevention* **13**: 279-289

Kline A, Strickler J, & Kempf J (1995) Factors associated with pregnancy and pregnancy resolution in HIV seropositive women. *Social Science & Medicine* **40**: 1539-1547

Kourtis AP (2002) Prevention of perinatal HIV transmission - Current status and future developments in anti-retroviral therapy. *Drugs* **62**: 2213-2220

Lewis JJ, Ronsmans C, Ezeh A, & Gregson S (2004) The population impact of HIV on fertility in sub-Saharan Africa. *AIDS* **18**: S35-43

Lush L (2002) Integrating HIV/STI and family planning services. Service integration: an overview of policy developments. *International Family Planning Perspectives* **28**: 71-76

Lutalo T, Kidugavu M, Wawer MJ, Serwadda D, Zabin LS, & Gray RH (2000) Trends and determinants of contraceptive use in Rakai District, Uganda, 1995-98. *Stud Fam Plann* **31**: 217-227

Ministry of Health Uganda (2005) *Uganda HIV/AIDS Sero-behavioural Survey 2004-05: Preliminary Report.* Ministry of Health, Kampala.

Murphy DA, Mann T, O'Keefe Z, & Rotheram-Borus MJ (1998) Number of pregnancies, outcome expectancies, and social norms among HIV-infected young women. *Health Psychology* **17**: 470-475

Nebie Y, Meda N, Leroy V, Mandelbrot L, Yaro S, Sombie I, Cartoux M, Tiendrebeogo S, Dao B, Ouangre A, Nacro B, Fao P, Ky-Zerbo O, Van de Perre P, & Dabis F (2001) Sexual and reproductive life of women informed of their HIV seropositivity: a prospective cohort study in Burkina Faso. *JAIDS* **28**: 367-372

Newell ML, Brahmbhatt H, & Ghys PD (2004) Child mortality and HIV infection in Africa: a review. *AIDS* **18**: S27-34

Njogu W (1991) Trends and determinants of contraceptive use in Kenya. *Demography* **28**: 83-99

Ntozi JP, Nakanaabi IM, & Lubaale YA (1997) Fertility levels and trends in the face of the AIDS epidemic in Uganda. *Health Transition Review* **7**: 145-155

Pool R, Nyanzi S, & Whitworth JA (2001) Attitudes to voluntary counselling and testing for HIV among pregnant women in rural south-west Uganda. *AIDS Care* **13**: 605-615

Ross A, Morgan D, Lubega R, Carpenter LM, Mayanja B, & Whitworth JA (1999) Reduced fertility associated with HIV: the contribution of pre-existing subfertility. *AIDS* **13**: 2133-2141

Ross A, Van der Paal L, Lubega R, Mayanja BN, Shafer LA, & Whitworth J (2004) HIV-1 disease progression and fertility: the incidence of recognized pregnancy and pregnancy outcome in Uganda. *AIDS* **18**: 799-804

Rothe JP (2000) *Undertaking Qualitative Research: Concepts and Cases in Injury, Health and Social Life.* Univ of Alberta Pubn Services: Edmonton, Alberta, Canada

Rutenberg N & Baek C (2005) Field Experiences Integrating Family Planning into Programs to Prevent Mother-to-Child Transmission of HIV. *Studies in Family Planning* **36**: 235-245

Rutenberg N & Baek C (2004) *Review of Field Experiences: Integration of Family Planning and PMTCT Services.* Population Council: Washington, DC.

Rutenberg N, Biddlecom AE, & Kaona FAD (2000) Reproductive decision-making in the context of HIV and AIDS: a qualitative study in Ndola, Zambia. *International Family Planning Perspectives* **26**: 124-129

Setel P (1995) The effects of HIV and AIDS on fertility in East and Central Africa. *Health Transition Review* **5**: 179-189

Sherr L, Hackman N, Mfenyana K, Chandia J, & Yogeswaran P (2003) Antenatal HIV testing from the perspective of pregnant women and health clinic staff in South Africa—implications for pre- and post-test counselling. *Counselling Psychology Quarterly* **16**: 337-347

Ssewanyana S & Younger SD (2005) *Infant Mortality in Uganda: Determinants, Trends, and the Millennium Development Goals.* Social Science Research Network

Thorne C & Newell ML (2003) Mother-to-child transmission of HIV infection and its prevention. *Current HIV Research* **1**: 447-462

Tuladhar JM (1985) Determinants of contraceptive use in Nepal. *J Biosoc Sci* **17**: 185-193

United Nations (1998) HIV/AIDS and Human Rights: International Guidelines.

United Nations (1994) Programme of Action of the United Nations International Conference on Population & Development.

United Nations Children's Fund (2005) UNICEF - Uganda - Statistics. http://www.unicef.org/infobycountry/uganda_statistics.html **Accessed: July 2007**

Wakabi W (2006) Population growth continues to drive up poverty in Uganda. *Lancet* **367**: 558

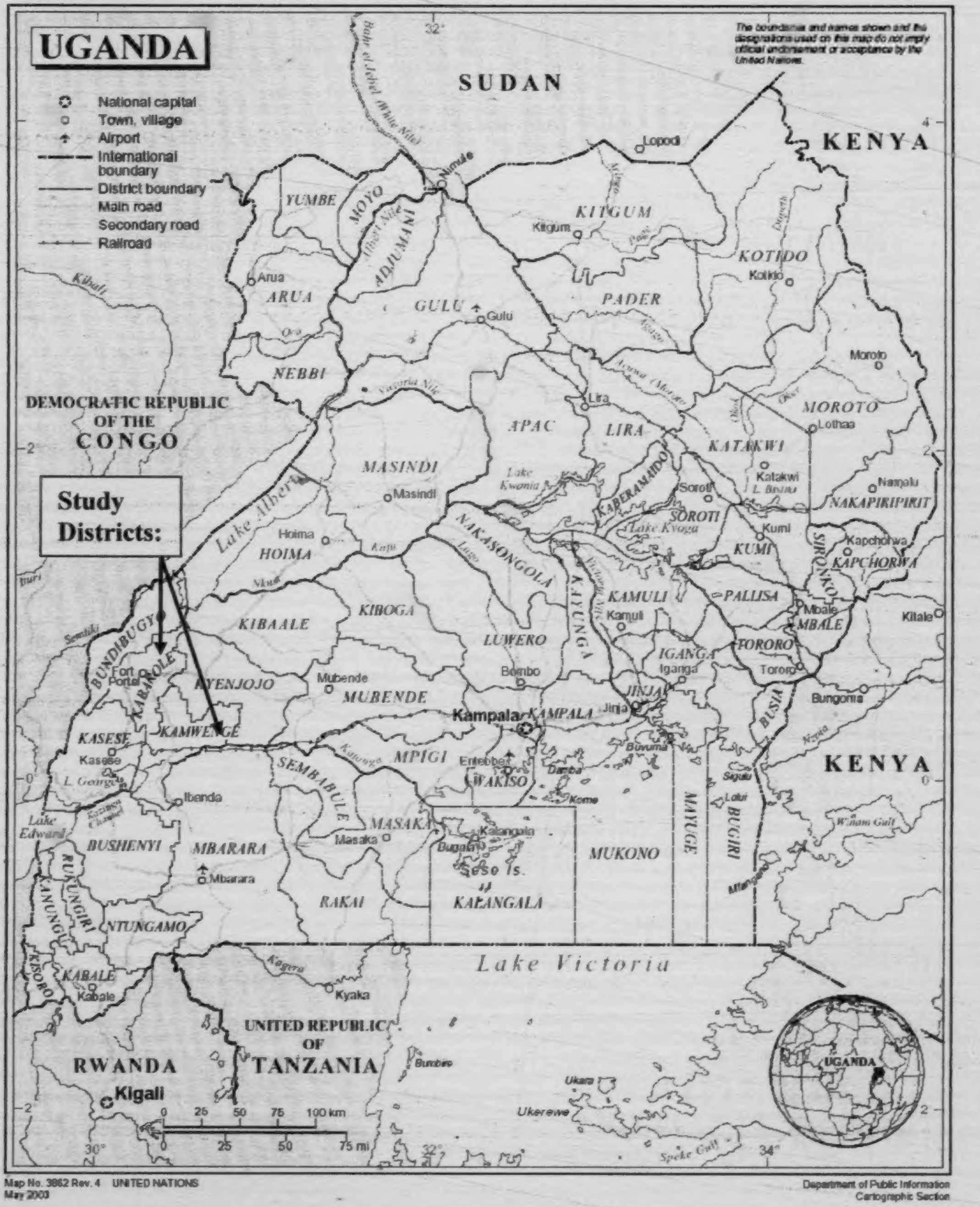
Wesley Y, Smeltzer SC, Redeker NS, Walker S, Palumbo P, & Whipple B (2000) Reproductive decision making in mothers with HIV-1. *Health Care Women Int* **21**: 291-304

Wolff B, Blanc AK, & Ssekamatte-Ssebuliba J (2000) The role of couple negotiation in unmet need for contraception and the decision to stop childbearing in Uganda. *Stud Fam Plann* **31**: 124-137

World Health Organization (2000) Fact Sheet Number 243 - Effectiveness of male latex condoms in protecting against pregnancy and sexually transmitted infections.

Appendices

Appendix A – Visual Representation of the Study Area



Source: United Nations, 2003: .
http://www.un.org/Depts/Cartographic/map/profile/uganda.pdf

Appendix B – Semi-Structured Interview Questionnaire

Reproductive Decision-Making in the Context of HIV/AIDS in Western Uganda

Semi-Structured Interview Questionnaire:

Date:___________________

Interviewer:___________________________________

ID Number:____________________ Partner ID #: __________________________

Recruitment Site: Rwimi Clinic ( ) Bigodi Support Group ( ) Other: ___________

Village:_________________________ Parish:______________________________

Part A: Demographics

1) Age:________

2) Sex: Male ( ) Female ( )

3) What is your marital status? Married ( ) Cohabiting ( )

4) Is the marriage official? (either introduction or wedding) Yes ( ) No ( )

5) Do you/your partner have more than one spouse? No ( ) Yes ( )
   If yes, how many in total? Number:_______________

6) Occupation: Peasant/farmer ( ) Businessman/woman (trading) ( ) Student ( )
   Housewife ( ) Professional (teacher, civil servant, doctor) ( ) Unemployed ( )
   Other:____

7) What type of house do you live in?
   a. Floor – mud ( ) wood ( ) cement/concrete ( ) other:_______________
   b. Walls – mud ( ) wood ( ) bricks ( ) grass/thatched ( ) other:_______
   c. Roof – iron sheets/other metals ( ) grass/thatched ( ) other:__________

8) Does the family own any of the following? Car ( ) Radio ( ) Television ( )
   Land ( ) Bicycle ( ) Poultry ( ) Animals ( ) Motorcycle ( )

9) Have you ever attended school? Yes ( ) No ( )

10) What is your highest level of education?

Lower primary – P1 to P4 ( ) Upper primary – P5 to P7 ( ) Lower secondary – S1 to S4 ( ) Upper secondary – S5 to S6 ( ) Technical/vocational ( ) College/university ( )

11) What is your religious affiliation? Protestant ( ) Catholic ( ) Muslim ( )
Seventh Day Adventist ( ) Pentecostal ( ) Other_________________ None ( )

12) How often do you attend religious services? More than once a week ( )
Once a week ( ) 1-3 times per month ( ) Less than once a month ( )

13) What is your tribe? Mutooro ( ) Muganda ( ) Munyankole ( ) Mukiga ( )
Mukonjo ( ) Other___________________

Part B: Reproductive Decision-Making in General

13B) Are you/Is your wife currently pregnant? Yes ( ) No ( ) Don't know ( )

14) How many children have you given birth to/fathered? (include miscarriages/stillbirths but exclude current pregnancy) ______________________

15) Are all still living? Yes ( ) No ( )

16) If no, how many are still alive? ______________________

17) Are you the primary caregiver for any children that you have not given birth to/fathered? Yes ( ) No ( )

18) If yes, how many? ______________________

19) Would you like to have (more) children? (After the child you are currently carrying is born?) Yes ( ) No ( ) If yes, go to question #25.

20) If question #19 is no: Why do you not wish to have (more) children?
Too expensive/Can't afford/Economic troubles ( ) HIV diagnosis (self or partner) ( )
Have enough already ( ) Other illness (self or partner) ( ) Partner doesn't want ( )
Too old ( ) Other:____

21) If reason for #20 is HIV diagnosis: If you/partner had tested negative rather than positive for HIV would you have wanted to have (more) children? Yes ( ) No ( )

22) If #21 is yes: How many (more) children would you have wanted to have if you had not been diagnosed with HIV? _____________________________________

23) Have you ever discussed stopping childbearing with your partner(s)?
Yes – with all partners ( ) Yes – not with all partners ( ) No ( ) If no or not with all, why? ____

24) Does whether or not you will stop childbearing depend more upon what your partner(s) want(s) or on what you want? (tick once for each spouse)
Partner ( ) Participant ( ) Equal (partner and participant) ( ) Other:_____________

Now go to question #30.

25) How many (more) children would you like to have? _____ (excluding pregnancy)

26) Why do you wish to have this many (more) children? ______________________

____

27) Have you ever discussed with your partner(s) the number of children you would like have together? Yes–with all partners ( ) Yes–not with all partners ( ) No ( ) If no or not with all, why? ____

28) If yes to question #27, how many more children does your spouse/spouses wish to have? ______________________________ (write the number for each spouse)

29) Does the number of children that you will have with your partner(s) depend more upon what your partner(s) wants or on what you want? (tick once for each spouse)

Partner ( ) Participant ( ) Equal (partner and participant) ( ) Other:__________

30) Have you or your partner ever used contraception? (PROMPT: including condoms) Yes ( ) No ( )

31) Are you or your partner currently using contraception? (PROMPT: including condoms) Yes ( ) No ( )

32) If no to question #31, why not? Side effects ( ) Describe side effects:

____

Partner opposition ( ) Want some/more children ( ) Too expensive ( ) Didn't know where to get it ( ) Clinic/store too far away ( ) Religious prohibition ( ) Stigma ( ) Partner would suspect me of cheating ( ) Currently pregnant or breastfeeding ( ) Other:________________

33) If yes to question #31: Which method(s) of contraception are you using?

OC pill ( ) Injectables ( ) Male condom ( ) Female condom ( ) Natural Family Planning ( ) Abstinence ( ) Sterilization – vasectomy/tubes tied ( )

Other: ___________________________________

34) Why did you choose this method of contraception instead of the other ones?

____

35) Have you ever wanted to use contraception and not been able to? Yes ( ) No ( )

36) If yes to #35, what prevented you from being able to use contraception?

Too expensive ( ) Didn't know where to get it ( ) Clinic/store too far away ( )

Partner opposed ( ) Religious prohibition ( ) Stigma ( ) Partner would suspect me of cheating ( ) Side effects ( ) If side effects, describe them: ________________

Other:____

37) For female participants only: If yes to question #31: Does your partner know that you are using contraception? Yes ( ) No ( ) Don't Know ( )

38) If no, why did you not tell him? ______________________________________

Part C: Reproductive Decision-Making and HIV

39) Have you tested for HIV? Yes ( ) No ( )

40) If yes, what were the results of the test? Positive ( ) Negative ( ) Don't Know ( )

40B) Did you receive your HIV test results today? Yes ( ) No ( )

41) If no to #40B: Did you inform your partner(s) of your HIV test results?

Yes – all of them ( ) Yes – not all of them ( ) No ( )

42) If no or not all, why not? ____

42B) If yes to #40B: Does your partner know that you came to be tested for HIV today? Yes ( ) No ( ) Don't know ( ) If no, why not? ____________________

43) Is/Are your partner/partners HIV infected? (tick once for each spouse)

Yes ( ) No ( ) Don't know ( )

If yes, check if their name is on our list so we can interview them. If the partner is positive and their name is not on the list then check if their partner is 18-44 years and not bedridden then they can participate in the study. If the partner is male, negative, 18-44 and from Rwimi (not Bigodi) then recruit the partner. DO NOT recruit negative women.

Is the partner recruited? Yes – recruited and interviewed ( ) Yes – recruited and flyer left for them ( ) No (reason why not):___________________________

IF THEY ARE BEING RECRUITED MAKE SURE TO RECORD THEIR NAME ON A DIFFERENT SHEET OF PAPER (write their name and their spouses name).

44) Have any of your family members died of AIDS? Yes ( ) No ( ) Maybe ( )

45) Do you know any children under age 10 who have died of AIDS?

Yes ( ) No ( ) Maybe ( )

HIV positive individuals only (questions 46-60):

46) Has the number of children you wish to have changed as a result of your HIV diagnosis? Yes ( ) No ( ) If no, why not? ______________________

____

If no, skip to question #52.

47) If yes, do you wish to have more children, less children, or stop childbearing? More ( ) Less ( ) Stop ( ) Why do you feel this way? ________________

____

48) If #47 is stop: Did you discuss stopping childbearing with your partner(s) at any time following your HIV diagnosis? Yes – all of them ( ) Yes – not all of them ( ) No ( ) If no or not with all, why?

____

49) If #47 is more or less: Did you discuss how many children you wish to have with your partner(s) at any time following your HIV diagnosis?
Yes – all of them ( ) Yes – not all of them ( ) No ( ) If no or not with all, why? ____

50) If #47 is more or less: Has the timing with which you wish to have children changed as a result of your HIV diagnosis? Yes ( ) No ( )

51) If yes to #50: Do you wish to have your children at a younger age or at an older age? Younger ( ) Older ( ) Why do you feel this way? ________________

____

52) Have you ever experienced any AIDS-related symptoms/illness? Yes ( ) No ( )

53) Are you taking antiretroviral treatment? (NOT Septrin)Yes ( ) No ( )

54) **For females:** Have you become pregnant after finding out that you are HIV positive? **For males:** Has your partner/Have any of your partners become pregnant after finding out that they are HIV positive? Yes ( ) No ( )
If no, go to question #65B.

55) Was this pregnancy planned? Yes ( ) No ( )

56) Did you/your partner receive PMTCT services? Yes ( ) No ( )

57) **Females**: Did you tell the health care worker(s) who you came into contact with during your pregnancy and/or delivery that you were HIV-positive? **Males with an HIV positive spouse**: Did your partner(s) tell the health care worker(s) who she came into contact with during her pregnancy and/or delivery that she was HIV-positive? Yes, always ( ) Yes, sometimes ( ) No, never ( ) Don't know ( )

58) If no or only sometimes to #57, why not? ________________________________

____

59) If yes to question #57: Did the health workers treat you/your partner(s) differently than they would another pregnant woman who was not infected with HIV? Yes ( ) No ( ) Don't know ( )

60) If yes to #59: Can you describe how they treated you/her/them differently?

____

HIV-negative participants only (questions 61-65):

61) If you tested positive for HIV today would that change the number of children you wish to have? Yes ( ) No ( ) If no, why not?___________________________

____

If no, skip to question #66.

62) If yes to #61, would you wish to have more children, less children, or stop childbearing? More ( ) Less ( ) Stop ( ) Why do you feel this way? _______

____

63) If #62 is more or less: How many more children would you wish to have if you became HIV positive today? _________ (excluding pregnancy)

64) If #62 is more or less: If you had been diagnosed with HIV would you change the age at which you had your future children? Yes ( ) No ( )

65) If yes to #64, would you wish to have your children at a younger age or at an older age? Younger ( ) Older ( ) Why do you feel this way? __________________

____

All respondents:

65B) Do you think that it is possible for HIV to be transmitted from a mother to her child either during pregnancy or during childbirth? Yes ( ) No ( ) Don't know ( )
If no or don't know, skip to question #70.

66) A) Do you think that HIV can be transmitted from mother to child during pregnancy and/or childbirth if the mother is not on ARVs and she gives birth in the village?

Yes ( ) No ( ) Don't know ( )

67) A) If yes to question #66A: If there were 10 HIV positive pregnant women who are not on ARVs and give birth in the village how many do you think would transmit HIV to their child? _____________ Don't know ( )

66B) Do you think that HIV can be transmitted from mother to child during pregnancy and/or childbirth if the mother is not on ARVs and she gives birth in the hospital?

Yes ( ) No ( ) Don't know ( )

67B) If yes to question #66B: If there were 10 HIV positive pregnant women who are not on ARVs and give birth in the hospital how many do you think would transmit HIV to their child? _____________ Don't know ( )

68) A) Do you think that HIV can be transmitted from mother to child during pregnancy and/or childbirth if the mother is receiving ARV treatment and gives birth in the village? Yes ( ) No ( ) Don't know ( )

69) A) If yes to question #68A: If there were 10 HIV positive pregnant women who were on ARV treatment and give birth in the village how many do you think would transmit HIV to their child? __________________ Don't know ( )

68B) Do you think that HIV can be transmitted from mother to child during pregnancy and/or childbirth if the mother is receiving ARV treatment and gives birth in the hospital? Yes ( ) No ( ) Don't know ( )

69B) If yes to question #68B: If there were 10 HIV positive pregnant women who were on ARV treatment and give birth in the hospital how many do you think would transmit HIV to their child? __________________ Don't know ( )

70) Do you think it is okay for women who have been diagnosed with HIV to become pregnant? Yes ( ) No ( ) Don't know ( ) Can you describe why you feel this way?____

____

71) A) Do you think it is okay for a HIV positive man to make his wife pregnant if he knows she is also HIV positive? Yes ( ) No ( ) Don't know ( ) Can you

describe why you feel this way?____

____

71) B) Do you think it is okay for a HIV negative man to make his wife pregnant if he knows she is HIV positive? Yes ( ) No ( ) Don't know ( ) Can you describe why you feel this way?____

____

72) Was risk of mother to child transmission discussed during the VCT (voluntary counseling and testing) process? Yes ( ) No ( ) Don't know ( )

73) Were contraceptive options discussed during the VCT (voluntary counseling and testing) process? Yes, condoms only ( ) Yes, condoms and other contraceptive methods ( ) No ( ) Don't know ( )

74) Would you be willing to participate in a focus group discussion to explore these questions in further detail, bearing in mind that others in the group may become aware that you were tested for HIV and what your HIV status is? Your medical treatment will not be affected in any way if you decline. Yes ( ) No ( )

Any other comments or questions:

____

____

____

____

Appendix C – Questions for Focus Group Discussion Sessions

Questions for Focus Group Discussions – HIV Positive Men/Women:

Thank you for being here today to take part in this focus group discussion. We would like to talk to you about childbearing and reproductive decisions. We are especially interested in your personal experiences as people living with HIV. Please feel free to share your own experiences or to talk generally about others you know without using their names. Please keep all the information we discuss here today confidential to protect yourself and the others in the group. At the beginning we will ask you questions in order to gain information. If you have questions or concerns about your personal health care that are not directly related to the study we will try to address them at the end of the session so please save them for this time.

Section 1: Reproductive Decision-Making in General

1) What are the things that promote childbearing? (I would like to know what they think about the following: having children to increase the clan, having children to work at home, having children to replace deceased children and having more children than they wish in case some die in the future)
2) What are the things that make people want to stop childbearing? (school fees, financial problems)
3) What tends to be the desired family for people in your village?
4) Do you think that most people are able to achieve their desired family size? If no, why not?
5) Are most pregnancies planned or unplanned?
6) Who tends to want more children, women or men?
7) Who decides how many children a couple will have, the husband or the wife?
8) Is it common for couples to discuss how many children they will have together?
9) Is it common for couples to use family planning?
10) Which methods of family planning are available to you at the shops or health centres near where you live? How much do they cost?
11) Which methods of family planning are most popular?
12) What are the reasons why people would be reluctant to use family planning? (discuss stigma and side effects – with women ask how many have heard of the continuous bleeding or over-bleeding problem and how many have ever personally experienced it)

Section 2: Reproductive Decision-Making and HIV

13) Does an HIV diagnosis have an effect on reproductive decisions?
14) If yes, what is the effect? Does it limit or increase childbearing?
15) Why does an HIV diagnosis have this effect on childbearing? What concerns people most about childbearing with HIV positive people?

16) If a couple is HIV positive and still wishes to have children should they have their children sooner (at a younger age) or wait longer to have children at an older age?
17) What would you think if you heard about a couple that was HIV positive and decided to have children?
18) Would your feelings differ if the couple did not have any children yet?
19) Would your feelings differ if they both had children with other partners but not together as a couple?
20) If an HIV positive couple does want to have a child what can they do to make the risk of transmission to the child less?
21) Is it important to deliver in a hospital rather than the village? Why?
22) How do ARVs influence the risk of mother to child transmission?

Section 3: Contact and Information from Health Care System

23) After you were told that you are HIV positive did the health care worker talk to you about childbearing or family planning? If so, what did they tell you?
24) Did you understand the information you were told during your counseling session? Do you remember it?
25) Do you think that you have all the information you need to make an informed decision about contraceptives?
26) Do you think that you have all the information you need about childbearing while HIV positive?
27) Are there any changes you would like to see in the HIV or family planning services offered at the Rwimi Health Centre?
28) Do you have any other questions or comments?

Questions for Focus Group Discussions – HIV Negative Men/Women:

Thank you for being here today to take part in this focus group discussion. We would like to talk to you about childbearing and reproductive decisions. Please feel free to share your own experiences or to talk generally about others you know without using their names. Please keep all the information we discuss here today confidential to protect yourself and the others in the group. At the beginning we will ask you questions in order to gain information. If you have questions or concerns about your personal health care that are not directly related to the study we will try to address them at the end of the session so please save them for this time.

Section 1: Reproductive Decision-Making in General

1) What are the things that promote childbearing? (I would like to know what they think about the following: having children to increase the clan, having children to work at home, having children to replace deceased children and having more children than they wish in case some die in the future)
2) What are the things that make people want to stop childbearing? (school fees, financial problems)
3) What tends to be the desired family for people in your village?

4) Do you think that most people are able to achieve their desired family size? If no, why not?
5) Are most pregnancies planned or unplanned?
6) Where do most women give birth? Who usually attends these births?
7) Who tends to want more children, women or men?
8) Who decides how many children a couple will have, the husband or the wife?
9) Is it common for couples to discuss how many children they will have together?
10) Is it common for couples to use family planning?
11) Which methods of family planning are available to you at the shops or health centres near where you live? How much do they cost?
12) Which methods of family planning are most popular?
13) What are the reasons why people would be reluctant to use family planning? (discuss stigma and side effects – with women ask how many have heard of the continuous bleeding or over-bleeding problem and how many have ever personally experienced it) Is there religious opposition to contraception that may be inhibiting people from using it?

Section 2: Reproductive Decision-Making and HIV

14) Would an HIV diagnosis have an effect on your reproductive decisions?
15) If yes, what is the effect? Does it limit or increase childbearing?
16) Why does an HIV diagnosis have this effect on childbearing? What concerns people most about childbearing with HIV positive people?
17) If a couple is HIV positive and still wishes to have children should they have their children sooner (at a younger age) or wait longer to have children at an older age?
18) What would you think if you heard about a couple that was HIV positive and decided to have children?
19) Would your feelings differ if the couple did not have any children yet?
20) Would your feelings differ if they both had children with other partners but not together as a couple?
21) If an HIV positive couple does want to have a child what can they do to make the risk of transmission to the child less?

Section 3: Contact and Information from Health Care System

22) Why do you think that so many more women than men test for HIV?
23) After you were told that you are HIV negative did the health care worker talk to you about childbearing or family planning? If so, what did they tell you?
24) Did you understand the information you were told during your counseling session? Do you remember it?
25) Do you think that you have all the information you need to make an informed decision about contraceptives?
26) Are there any changes you would like to see in the HIV or family planning services offered at the Rwimi Health Centre?
27) Do you have any other questions or comments?

Health Care Worker Focus Group Discussion Questions:

1) What HIV-related services are offered at the Rwimi Health Centre? What is the cost to the patient for these services?
2) Can you describe the VCT process? What information is told to patients during their VCT session?
3) Does the information given during the VCT session differ depending upon the patient? For example, is different information given to men and women? Or to pregnant vs. non-pregnant women?
4) What are HIV positive clients advised about having children? Does this differ depending upon whether the client is on ARVs or not? Do you think most clients will heed this advice or is the desire for children so strong that many of them will go ahead and have children anyways?
5) If a client is HIV positive but insists on having more children what advice do you give them? (i.e. about waiting longer between pregnancies) Does this happen frequently?
6) Do you see many women who already know their status coming to the clinic for antenatal care or PMTCT (meaning those who found out before they conceived)?
7) Do most women in the area deliver their children in the village or in a hospital or health centre?
8) What happens to the risk of HIV transmission if a woman delivers in the village rather than in the hospital/clinic? (talk about "milking the cord" and other practices that could lead to increased transmission)
9) Why do you think that so many more women than men test for HIV?
10) What family planning services are offered at the Rwimi Health Centre?
11) Which methods of family planning are available at the clinic?
12) What are the barriers that restrict clients from using contraception?
    a. Cost?
    b. Religious prohibition?
    c. Fear of side effects (such as continuous blood flow)? Does the continuous blood flow side effect occur often? What is the cause of this?
    d. Stigma (such as rumors that contraception causes HIV and/or cancer)? Are these rumors common? What should be done to stop them?
13) Is there any integration of the HIV-related and family planning services at the clinic? For example, are contraceptive methods discussed during VCT and/or with ART patients? If so, which methods are mentioned? Can an ART patient get family planning while they see the doctor for their CD4 test or are they then referred to the outpatient ward?
14) Are HIV positive clients advised differently with respect to family planning? For example, are they encouraged to use condoms or dual method protection (condoms plus another method)? Are they advised to not use oral contraceptives if they are on ARVs?

15) What are the biggest challenges you are having here at the health centre with respect to the HIV and/or family planning services you offer?

Questions for Focus Group Discussions – HIV Positive Women who have Given Birth Following their Diagnosis:

Thank you for being here today to take part in this focus group discussion. We would like to talk to you about childbearing and reproductive decisions. Please feel free to share your own experiences or to talk generally about others you know without using their names. Please keep all the information we discuss here today confidential to protect yourself and the others in the group. At the beginning we will ask you questions in order to gain information. If you have questions or concerns about your personal health care that are not directly related to the study we will try to address them at the end of the session so please save them for this time.

Section 1: Reproductive Decision-Making in General

1) What are the things that promote childbearing? (I would like to know what they think about the following: having children to increase the clan, having children to work at home, having children to replace deceased children and having more children than they wish in case some die in the future)
2) What are the things that make people want to stop childbearing? (school fees, financial problems)
3) What tends to be the desired family for people in your village?
4) Do you think that most people are able to achieve their desired family size? If no, why not?
5) Are most pregnancies planned or unplanned?
6) Where do most women give birth? Who usually attends these births?
7) Who tends to want more children, women or men?
8) Who decides how many children a couple will have, the husband or the wife?
9) Is it common for couples to discuss how many children they will have together?
10) Is it common for couples to use family planning?
11) Which methods of family planning are available to you at the shops or health centres near where you live? How much do they cost?
12) Which methods of family planning are most popular?
13) What are the reasons why people would be reluctant to use family planning? (discuss stigma and side effects – with women ask how many have heard of the continuous bleeding or over-bleeding problem and how many have ever personally experienced it) Is there religious opposition to contraception that may be inhibiting people from using it?

Section 2: Reproductive Decision-Making and HIV

We understand that all of you have become pregnant after knowing you were HIV positive and wish to ask you some questions about this if it is okay with you. We are not here to counsel you or tell you what to do/what not to do but just to better understand your feelings and situations you have been in.

14) Did you plan to become pregnant after you knew you were diagnosed? If so, why? If not, what led to you becoming pregnant?
15) Were you fearful during your pregnancy for reasons related to your HIV diagnosis? If so, what worries did you have?
16) Did you seek medical attention during this pregnancy, delivery and/or antaenatal care? If so, what type? If not, why not?
17) Were the medical staff that you came into contact with during this time know that you were HIV positive? If so, did they treat you differently than the pregnant women who were not HIV positive? If so, how? Were the medical staff ever rude to you or did they reprimand you for getting pregnant when you knew that you were HIV positive?
18) Did people in your village know that you gave birth while knowing you were HIV positive? If so, did they comment on it? If so, what did they say? What do you think that others in the village think about HIV positive women who have children?
19) Did your HIV diagnosis have an effect on your reproductive decisions? If yes, what was the effect?

Section 3: Contact and Information from Health Care System

20) Why do you think that so many more women than men test for HIV?
21) After you were told that you are HIV positive did the health care worker talk to you about childbearing or family planning? If so, what did they tell you?
22) Did you understand the information you were told during your counseling session? Do you remember it?
23) Do you think that you have all the information you need to make an informed decision about contraceptives?
24) Do you think that you have all the information you need to make informed decisions about childbearing while HIV positive?
25) Are there any changes you would like to see in the HIV or family planning services offered in your area?
26) Do you have any other questions or comments?

Appendix D – Invitation Letter for Field Recruitment

UNIVERSITY OF
ALBERTA

Department of Public Health Sciences **Recruitment Letter**

Reproductive Decision-Making in Western Uganda

Dear Mr./Mrs. ___________

You are eligible to participate in a research study. This study is being conducted by researchers from the University of Alberta in Canada. The purpose of this study is to find out how people in western Uganda feel about having children. If you choose to participate in this study you will be involved in a 30 minute interview either at your home or at the Rwimi Health Center. You may choose to not participate in this study, as participation is completely voluntary.

Thank you.

Participant name: ___________________________________

Please check:

Are they married? Yes ( ) No ( ) If no, they cannot participate.
Are they 18-44 years? Yes ( ) No ( ) If no, they cannot participate.
Are they bedridden? Yes ( ) No ( ) If yes, they cannot participate.
Are they interested in participating in the study? Yes ( ) No ( )

If they meet the criteria and agree to participate then ask them:
Would you like to come to the clinic for the interview or have us come to your home? We will reimburse your transport costs if you choose to come to the clinic.
Clinic ( ) Home ( )

If they would like to come to the clinic please invite them to come on the next Monday, Wednesday or Friday between 11 am and 3 pm. If they would like us to come to their home, please make an appointment for as soon as possible on a Monday, Wednesday or Friday between 11 am and 3 pm.

Appendix E – Invitation Letter (Participant not present)

UNIVERSITY OF ALBERTA

Department of Public Health Sciences

Recruitment Letter

Name:________________________ ID#: ______________

You are eligible to participate in a research study. This study is being conducted by researchers from the University of Alberta in Canada. The purpose of this study is to find out how people in western Uganda feel about having children. If you choose to participate in this study you will be involved in a 30 minute interview either at your home or at the Rwimi Health Center. You may choose to not participate in this study, as participation is completely voluntary. If you decide not to participate in this study your medical treatment will not be affected in any way.

If you are interested in participating in this study or would like to find out more information please contact the Clinical Officer in person at the Rwimi Health Center on any Monday, Wednesday or Friday in October or November of 2006 (11am – 3pm). You will be reimbursed for your transport expenses between your home and the health center.

Thank you.

Appendix F – Invitation Form for Clinic Recruitment

UNIVERSITY OF ALBERTA

Department of Public Health Sciences **Recruitment Letter**

Recruitment Letter for Rwimi Clinic Post-Test Clients:

Name:________________________

Client #:__________

ID #:_____________ **(to be filled out by research team)**

Please fill in the following information:

Is the client married or cohabiting? Yes ( ) No ( )
Is the client 18-44 years? Yes ( ) No ( )
Is the client HIV negative? Yes ( ) No ( )

If yes to all of the questions above please ask the client the following question:

Are you interested in participating in a research study about childbearing that will take about one hour of your time? Yes ( ) No ( )

If the answer to the last question is yes then please send the client to Jennifer with this form.

Appendix G – Invitation Letter for Focus Group Discussion Sessions

UNIVERSITY OF
ALBERTA
Department of Public Health Sciences

Recruitment Letter

Dear Mr./Mrs. ____________________ ID#:____________

We wish to thank you for your previous participation in the Reproductive Decision-Making study. The same researchers from the University of Alberta in Canada have now selected you to participate in a focus group to explore the issues from the questionnaires in further detail. The focus group will be a 45-90 minute discussion with a group of 5-10 individuals. It will be conducted at the Rwimi Health Centre on:
______________________________ at: ____________________.
If you choose to participate in the focus group discussion your transport costs to and from the clinic will be reimbursed.

You do not have to participate in the focus group discussion. If you do decide to participate you must be aware that the other members of the group will become aware that you were tested for HIV and what your HIV status is. If you choose not to participate in the focus group your medical treatment will not be affected in any way.

Thank you.

Appendix H – Information Letter for Interviews

KABAROLE DISTRICT
MEDICAL DEPARTMENT
P.O. BOX 38
FORT PORTAL

Tel/Fax: 00256 483 23043

IN ANY CORRESPONDENCE ON
THIS SUBJECT PLEASE QUOTE No. HEA/

Information Letter Semi-Structured Interviews

Study Title:
Reproductive Decision-Making in the Context of HIV/AIDS in Kabarole District, Uganda

Investigators

Jennifer Heys, Department of Public Health Sciences, University of Alberta, phone 0774301788
Tom Rubaale, Health Department, Fort Portal, phone 0782856865
Dr. Walter Kipp, Department of Public Health Sciences, University of Alberta 17804699905

Study Purpose

The purpose of this study is to find out which factors influence western Ugandans in their decision whether or not to have children. We also wish to determine if an HIV diagnosis has an effect on whether or not western Ugandans want to have more children. Our final objective is to explore the reasons why western Ugandans may not be able to have the number of children that they want. Views of health care workers and patients who have tested HIV positive and HIV negative will be represented in this study.

Study Background

The study aims to find out what makes people in Kabarole district decide to have more children or to stop childbearing. This includes seeing how decisions about having children might change if a person finds out they are HIV positive. You are being asked to participate in this study either because you have been tested for HIV or because you are a health care worker. The results of the study will be used by the University of Alberta, the Kabarole Health Department and Makerere University to see how well HIV/AIDS and family planning programs are working.

Study Title:
Reproductive Decision-Making in the Context of HIV/AIDS in Kabarole District, Uganda

Procedures for Semi-Structured Interview

Semi-structured interview: You are being asked to participate in an interview session where you will answer questions related to HIV/AIDS and having children. Your answers will be written down by the research assistant and the interview will take about 30 minutes to complete. It is possible that the researcher will come to speak to you at a time after the interview is completed to ask a few more questions.

Confidentiality

All information collected will be kept confidential. Your name or other information that could identify you will not appear on the interview sheets. Only the university researchers will have access to your information. Two copies of the information will be made. One copy will be kept in Fort Portal in a locked cabinet in the office of Tom Rubaale. The other copy will be kept in a locked cabinet in the office of Walter Kipp at the Department of Public Health Sciences, University of Alberta, Canada. Information will be kept for five years, and then destroyed.

Benefits

Participants have the opportunity to potentially improve HIV/AIDS or family planning services. Answers provided by participants will help the Kabarole Health Department to see how well HIV/AIDS and family planning programs are working. They also may influence the Kabarole Health Department to make changes in these programs if the results show that there are some problems with these services. The results of the study may be shared with researchers, health workers and students in Uganda and Canada and may be published in international journals.

Risks

There is a chance that participants may become emotional or stressed when discussing the topic of HIV/AIDS or having children. You may choose to leave the interview or focus group session at any time if this occurs. You do not have to give a reason, and your answers will not be used. If you become distressed we have the phone number of a social worker available who you may contact if you wish.

Freedom to withdraw

Participation is entirely your choice. You may refuse to participate in this study. You are free to leave at any time. You do not have to answer any question that you do not want to answer. If you choose to not participate in the study or to withdraw from the study at any time your treatment and medical care will not be affected in any way.

Contact

If you have any concerns about anything to do with this study, you may contact the Health Department, Fort Portal, attention Tom Rubaale, phone 0782856865.

Appendix I – Consent Form

UNIVERSITY OF
ALBERTA

Department of Public Health Sciences Consent Form

Reproductive Decision-Making in the Context of HIV/AIDS in Kabarole District, Uganda

Part 1: Researcher Information

Primary Researcher:	Jennifer Heys
Affiliation:	Dept. of Public Health Sciences, University of Alberta, Edmonton, Canada
Contact Information:	Phone: 0774301788, E-mail: jheys@ualberta.ca
Field Supervisor:	Tom Rubaale
Affiliation:	Health Department, Fort Portal
Contact Information:	Phone: 0782856865, E-mail: walter.kipp@ualberta.ca
Thesis Supervisor:	Dr. Walter Kipp
Affiliation:	University of Alberta, Edmonton, Canada
Contact Information:	Telephone (Canada) 01-780-492-8643, E-mail: walter.kipp@ualberta.ca

Part 2: Consent of Subject

	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet? (or had it read to you)		
Do you understand the benefits and risks involved in taking part in this study?		
Have you been able to ask questions and discuss the study?		
Do you understand that you can refuse to be in the study or stop being in the study at any time? You do not have to give a reason.		
Do you agree to have a researcher contact you after the interview or focus group session to ask a few more questions, if required?		
Do you understand who will have access to your records/information?		
Do you agree to allow the researcher to write down your responses?		
Do you agree to allow the researcher to audio-record your responses? (focus groups only)		

Part 3: Signatures

This study was explained to me by (print name of research team member):

____

On (date): ______________________

I agree to take part in this study.

Name of Research Participant (*print*): ________________________________

Signature or Thumbprint of Research Participant: ____________________________

Witness (if available): ______________________________

Witness Signature or Thumbprint: ______________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Research Team Member who obtained participant consent:

____

Date Consent Received: ______________________

Appendix J – Information Letter for Focus Group Discussion Sessions

THE REPUBLIC OF UGANDA

Tel/Fax: 00256 483 23043

IN ANY CORRESPONDENCE ON
THIS SUBJECT PLEASE QUOTE No. HEA/

Information Letter for Focus Group Discussions

Study Title:
Reproductive Decision-Making in the Context of HIV/AIDS in Kabarole District, Uganda

Investigators

Jennifer Heys, Department of Public Health Sciences, University of Alberta, phone 0774301788
Tom Rubaale, Health Department, Fort Portal, phone 0782856865
Dr. Walter Kipp, Department of Public Health Sciences, University of Alberta 17804699905

Study Purpose

The purpose of this study is to find out which factors influence western Ugandans in their decision whether or not to have children. We also wish to determine if an HIV diagnosis has an effect on whether or not western Ugandans want to have more children. Our final objective is to explore the reasons why western Ugandans may not be able to have the number of children that they want. Views of health care workers and patients who have tested HIV positive and HIV negative will be represented in this study.

Study Background

The study aims to find out what makes people in Kabarole district decide to have more children or to stop childbearing. This includes seeing how decisions about having children might change if a person finds out they are HIV positive. You are being asked to participate in this study either because you have been tested for HIV or because you are a health care worker. The results of the study will be used by the University of Alberta, the Kabarole Health Department and Makerere University to see how well HIV/AIDS and family planning programs are working.

Study Title:
Reproductive Decision-Making in the Context of HIV/AIDS in Kabarole District, Uganda

Procedures for Focus Group Sessions

You are being asked to take part in a focus group discussion where you will answer questions. Between 4 and 9 other people will also be answering questions in this discussion. HIV/AIDS and having children will be the main topics of these questions. The focus group discussion session will take approximately 45-90 minutes. Your answers will be tape recorded by a researcher. It is possible that the researcher will come to speak to you after the focus group is completed to ask a few more questions.

Confidentiality

All information collected will be kept confidential. Your name or other information that could identify you will not appear on the interview sheets. Only the university researchers will have access to your information. Two copies of the information will be made. One copy will be kept in Fort Portal in a locked cabinet in the office of Tom Rubaale. The other copy will be kept in a locked cabinet in the office of Walter Kipp at the Department of Public Health Sciences, University of Alberta, Canada. Information will be kept for five years, and then destroyed.

Benefits

Participants have the opportunity to potentially improve HIV/AIDS or family planning services. Answers provided by participants will help the Kabarole Health Department to see how well HIV/AIDS and family planning programs are working. They also may influence the Kabarole Health Department to make changes in these programs if the results show that there are some problems with these services. The results of the study may be shared with researchers, health workers and students in Uganda and Canada and may be published in international journals.

Risks

There is a chance that participants may become emotional or stressed when discussing the topic of HIV/AIDS or having children. You may choose to leave the interview or focus group session at any time if this occurs. You do not have to give a reason, and your answers will not be used. If you become distressed we have the phone number of a social worker available who you may contact if you wish.

Freedom to withdraw

Participation is entirely your choice. You may refuse to participate in this study. You are free to leave at any time. You do not have to answer any question that you do not want to answer. If you choose to not participate in the study or to withdraw from the study at any time your treatment and medical care will not be affected in any way.

Contact

If you have any concerns about anything to do with this study, you may contact the Health Department, Fort Portal, attention Tom Rubaale, phone 0782856865.

Appendix K – Frequency Data from Interviews

Section 1: Sociodemographics			
Variable	**Label**	**n=421**	**%**
Recruitment Site	Rwimi	325	77%
	Bigodi	26	6%
	Kibiito	70	17%
Age	18-24	94	22%
	25-29	79	19%
	30-34	102	24%
	35-39	84	20%
	40-44	62	15%
Sex	Female	270	64%
	Male	151	36%
Marital Status	Married	254	60%
	Cohabiting	164	39%
	Combination	3	1%
# Spouses	1	406	96%
	2	14	3%
	3	1	0.2%
Occupation	Farmer/peasant	319	76%
	Businessperson	41	10%
	Unemployed	14	3%
	Professional	7	2%
	Security	7	2%
	Farmer and other	6	1%
	Textiles	5	1%
	Food	5	1%
	Other	17	4%
Dwelling Floor	Cement/concrete	36	9%
	Mud	382	91%
	Other materials	3	1%
Dwelling Walls	Bricks	38	9%
	Mud	368	87%
	Mud and other	12	3%
	Other	3	1%
Dwelling Roof	Metal	370	88%
	Grass/thatched	51	12%
Car Ownership	Yes	3	1%
	No	418	99%
Radio Ownership	Yes	341	81%
	No	80	19%
TV Ownership	Yes	6	1%
	No	415	99%

Land Ownership	Yes	363	86%
	No	68	14%
Bicycle Ownership	Yes	176	42%
	No	245	58%
Animal Ownership	Yes	242	57%
	No	179	43%
Poultry Ownership	Yes	294	70%
	No	127	30%
Motorcycle Ownership	Yes	13	3%
	No	408	97%
Attended School	Yes	351	83%
	No	70	17%
Education	None	70	17%
	Lower Primary	121	31%
	Upper Primary	164	39%
	Lower Secondary	45	11%
	Upper Secondary	3	0.7%
	Technical/Vocational	1	0.2%
	College/University	7	2%
Religion	Catholic	175	42%
	Protestant	157	37%
	Pentecostal	36	9%
	Muslim	30	7%
	Seventh Day	19	5%
	Mwikiriza	4	1%
Religiosity	Less than once a week	81	19%
	Once a week	324	77%
	1-3 times per month	13	3%
	Less than once a month	3	1%
Tribe	Mutooro	150	36%
	Mukiga	157	37%
	Munyankole	35	8%
	Mukonjo	47	11%
	Muganda	10	2%
	Mufumbira	9	2%
	Munyarwanda	4	1%
	Other	8	2%
	Missing	1	0.2%
Section 2: Childbearing General			
Variable	**Label**	**n=421**	**%**
Pregnant	Yes	156	37%
	No	206	49%
	Don't Know	3	1%
	Missing	56	13%

Number of Pregnancies for participant/partners	0	9	2%
	1	39	9%
	2	52	12%
	3	56	13%
	4	68	16%
	5	63	15%
	6	45	11%
	7	36	9%
	8	24	6%
	9	8	2%
	10	11	3%
	11+	10	2%
Are all children still alive?	Yes	215	41%
	No	172	51%
	Never had a child	34	8%
Number of Living children	0	45	11%
	1	58	14%
	2	57	14%
	3	65	15%
	4	75	18%
	5	45	11%
	6	35	8%
	7	19	5%
	8	10	2%
	9	5	1%
	10+	7	2%
Does participant care for non-bio children?	Yes	193	46%
	No	228	54%
Number of non-biological children	0	228	54%
	1	54	13%
	2	64	15%
	3	37	9%
	4	18	4%
	5	9	2%
	6	6	1%
	7+	5	1%
Do you want (more) children?	Yes	145	34%
	No	275	65%
	Other	1	0.2%

Why do you not want to have (more) children? Note: 276 respondents answered this question and gave a total of 344 responses (>1 response per person allowed).	HIV diagnosis	118	34%
	Has enough already	107	31%
	Economic reasons	76	22%
	Too old	8	2%
	No/not enough land	7	2%
	Problems in pregnancy	7	2%
	Other illness	6	2%
	Infertile	5	2%
	Other	10	3%
Want kids if HIV- instead of HIV+?	Yes	65	15%
	No	50	11%
	Missing	306	73%
How many kids if HIV- instead of HIV+	1	13	3%
	2	34	8%
	3	10	2%
	4+	7	2%
	Missing	357	85%
Have you discussed stopping childbearing with your partner?	Yes – with all spouses	249	59%
	Yes – not with all spouses	2	0.5%
	No	23	5%
	Missing	147	35%
Does stopping childbearing depend more upon what you want or your partner?	Equal	211	50%
	Participant	40	10%
	Partner	22	5%
	Missing	148	35%
Number more kids desired	0	275	65%
	1	41	10%
	2	47	11%
	3	33	8%
	4	13	3%
	5+	11	3%
	Up to God	1	0.2%
Why do you want this many more children? Note: 146 respondents answered this question and gave a total of 161 responses (>1 response per person allowed).	Can manage/afford	42	26%
	Not yet reached desired #	33	21%
	Expand clan	14	9%
	Searching for specific sex	13	8%
	No child yet	11	7%
	Partner's wishes	10	6%
	Replacement	8	6%
	Insurance	7	4%
	Care for house/parents	6	4%
	No reason to stop	4	3%
	Religious beliefs	3	2%
	Other	10	6%

Have you discussed # of children you wish to have with your partner?	Yes – with all spouses	110	26%
	No	34	8%
	Missing	277	66%
Number more children partner desires Note: data only obtained for participants who wanted more children	0	7	2%
	1	20	5%
	2	37	9%
	3	18	4%
	4	9	2%
	5+	9	2%
	Unsure	9	2%
	Up to God	2	0.5%
	Missing	310	74%
Does number of children you will have depend more upon what you want or your partner?	Equal	88	21%
	Participant	38	9%
	Partner	17	4%
	Missing	278	66%
Section 3: Family Planning Use			
Variable	**Label**	**n=421**	**%**
Ever used FP?	Yes	274	65%
	No	144	34%
	Missing	3	1%
Currently using FP?	Yes	176	42%
	No	239	57%
	Don't Know	2	0.5%
	Missing	4	1%
Those at risk of pregnancy currently using FP?	Yes	168	40%
	No	74	18%
	Don't Know	2	0.5%
	Missing	177	42%
Currently using an effective method of FP?	Yes	52	12%
	No	369	88%
Those at risk of pregnancy currently using an effective method of FP?	Yes	51	12%
	No	193	46%
	Missing	177	42%
Why not currently using FP? Note: 237 respondents answered this question and gave a total of 254 responses (>1 response per person allowed).	Pregnant/breastfeeding	117	46%
	Want some/more children	47	19%
	Side effects	31	12%
	Stigma	16	6%
	Partner opposition	13	5%
	Newlywed	8	3%
	Subfecund/infecund	6	2%
	Other	16	6%

FP method currently using	Male condom	128	30%
	Injectables	21	5%
	OC Pill	10	2%
	Dual method	8	2%
	Tubal ligation	6	1%
	Abstinence	5	1%
	Withdrawal	2	0.5%
	Vasectomy	1	0.2%
	Natural FP	1	0.2%
	Norplant	1	0.2%
	Missing	238	57%
Why did you choose this FP method? Note: 170 respondents answered this question and gave a total of 197 responses (>1 response per person allowed).	Avoid (re)infection	70	36%
	Convenience	36	18%
	HCW advice	25	13%
	Pregnancy prevention	24	12%
	Avoid side effects	21	11%
	Method is effective	4	2%
	Partner's wishes	4	2%
	On ARVs	4	2%
	Only known method	3	2%
	Other	6	3%
Ever wanted to use contraception and not been able to?	Yes	95	23%
	No	320	76%
	Missing	6	1%
What prevented you from using FP? Note: 92 respondents answered this question and gave a total of 95 responses (>1 response per person allowed).	Side effects	64	67%
	Stigma	9	10%
	Partner opposed	6	6%
	Conceived while using FP	5	5%
	Forgetful	4	4%
	Too expensive	2	2%
	Clinic/store too far	2	2%
	Other	3	3%
Side effects symptoms Note: 60 respondents answered this question and gave a total of 74 responses (>1 response per person allowed).	Heavy/long periods	35	47%
	Weakness	11	15%
	Dizziness	7	10%
	High bp/rapid heartbeat	4	5%
	Amenorrhea	4	5%
	Weight loss/gain	4	5%
	Other	9	12%
Does your husband know you are using FP?	Yes	3	1%
	No	95	23%
	Missing	323	77%

Section 4: HIV/AIDS Characteristics

Variable	**Label**	**n=421**	**%**
HIV Status	Positive	199	47%
	Negative	222	53%

HIV test results received today?	Yes	172	41%
	No	241	57%
	Yes and No	8	2%
HIV status disclosure to partner? (n=246)	Yes	239	57%
	No	5	1%
	Not with all partners	2	0.5%
	Missing	175	42%
Testing disclosure to partner?	Yes	147	35%
	No	28	7%
	Missing	246	58%
Partner HIV Status	Positive	132	31%
	Negative	137	33%
	Don't Know	147	35%
	Other	5	1%
AIDS Death in Family	Yes	256	61%
	No	163	39%
	Don't Know	1	0.2%
	Missing	1	0.2%
AIDS Death of Child	Yes	105	25%
	No	311	74%
	Don't Know	4	1%
	Missing	1	0.2%
Section 5: HIV/AIDS and Childbearing			
Variable	**Label**	**n=421**	**%**
Desired children changed as result of HIV diagnosis?	Yes	102	24%
	No, Didn't make diff	10	2%
	No, already decided to stop	86	20%
	Missing	223	53%
Did diagnosis make you want more children, less children, or stop childbearing?	More	1	0.2%
	Less	14	3%
	Stop	87	21%
	Missing	319	76%
Discuss stopping childbearing with partner after diagnosis?	Yes	68	16%
	No	7	2%
	Missing	346	82%
Discuss how many children to have with partner after diagnosis?	Yes	13	3%
	No	2	0.5%
	Missing	406	96%
Childbearing timing changed after diagnosis?	Yes	10	2%
	No	5	1%
	Missing	406	96%
Have children at younger or older age?	Younger	5	1%
	Older	5	1%
	Missing	411	98%

Experienced AIDS symptoms?	Yes	130	31%
	No	69	16%
	Missing	222	53%
Taking ARV treatment?	Yes	122	29%
	No	77	18%
	Missing	222	53%
Pregnant post diagnosis?	Yes	15	4%
	No	184	44%
	Missing	222	53%
Pregnancy planned?	Yes	1	0.2%
	No	14	3%
	Missing	406	96%
PMTCT services?	Yes	10	2%
	No	5	1%
	Missing	406	96%
Serostatus disclosure to HCWs?	Yes	10	2%
	No	5	1%
	Missing	406	96%
Treated differently than a HIV- woman?	Yes	3	1%
	No	7	2%
	Missing	411	98%
Desired children would change as result of HIV diagnosis?	Yes	131	31%
	No, Didn't make diff	14	3%
	No, already decided to stop	77	18%
	Missing	199	47%
Would diagnosis make you want more children, less children, or stop childbearing?	Less	21	5%
	Stop	110	26%
	Missing	290	69%
How many more children if diagnosed HIV+?	1	9	2%
	2	8	2%
	3	5	1%
	Missing	399	95%
Childbearing timing would change if HIV+?	Yes	19	5%
	No	4	1%
	Missing	398	95%
If HIV+, have children at younger or older age?	Younger	8	2%
	Older	11	3%
	Missing	402	95%
Why have children at younger age if HIV+?	Have children before dying	5	1%
	Now strong, may weaken	4	1%
	Raise children before dying	3	1%
	Financial reasons	1	0.2%
	Missing	408	97%

Why have children at older age if HIV+?	First gain strength	10	2%
	ARV side effects cease	2	0.5%
	HCW advice	2	0.5%
	Child spacing	1	0.2%
	Plan for children first	1	0.2%
	Missing	405	96%
Section 6: Knowledge Regarding MTCT			
Variable	**Label**	**n=421**	**%**
MTCT possible?	Yes	394	94%
	No	14	3%
	Don't Know	12	3%
	Missing	1	0.2%
MTCT possible if not on ARVs?	Yes	68	16%
	No	3	1%
	Don't Know	1	83%
	Missing	349	0.2%
# HIV+ babies if 10 HIV+ mothers not on ARVs	0	3	1%
	1-2	3	1%
	3-4	8	2%
	5-6	15	4%
	7-8	15	4%
	9-10	19	5%
	Don't Know	8	2%
	Missing	350	83%
MTCT possible if on ARVs?	Yes	31	7%
	No	39	9%
	Don't Know	7	2%
	Missing	344	82%
# HIV+ babies if 10 HIV+ mothers on ARVs	0	39	9%
	1-2	5	1%
	3-4	5	1%
	5-6	10	2%
	7-8	3	1%
	9-10	4	1%
	Don't Know	2	0.5%
	Missing	353	84%
MTCT possible if village birth and no ARVs?	Yes	324	77%
	Don't Know	1	0.2%
	Missing	96	23%
# HIV+ babies if 10 HIV+ mothers not on ARVs give birth in village	3-4	5	1%
	5-6	33	8%
	7-8	48	11%
	9-10	206	49%
	Don't Know	31	7%
	Missing	98	23%

MTCT possible if hospital birth and no ARVs?	Yes	153	36%
	No	165	39%
	Don't Know	5	1%
	Missing	98	23%
# HIV+ babies if 10 HIV+ mothers not on ARVs give birth in hospital	0	167	40%
	1-2	11	3%
	3-4	13	3%
	5-6	52	12%
	7-8	23	5%
	9-10	38	9%
	Don't Know	14	3%
	Missing	103	24%
MTCT possible if village birth and ARVs?	Yes	196	47%
	No	96	23%
	Don't Know	27	6%
	Missing	102	24%
# HIV+ babies if 10 HIV+ mothers on ARVs give birth in village	0	96	23%
	1-2	6	1%
	3-4	13	3%
	5-6	38	9%
	7-8	37	9%
	9-10	82	19%
	Don't Know	21	5%
	Missing	128	30%
MTCT possible if hospital birth and ARVs?	Yes	37	9%
	No	261	62%
	Don't Know	21	5%
	Missing	102	24%
# HIV+ babies if 10 HIV+ mothers on ARVs give birth in hospital	0	261	62%
	1-2	11	3%
	3-4	7	2%
	5-6	11	3%
	7-8	1	0.2%
	9-10	4	1%
	Don't Know	4	1%
	Missing	122	29%
MTCT Understanding	Low	307	73%
	High	114	27%
MTCT Risk Understanding	Yes	235	56%
	No	159	38%
	Missing	27	6%
MTCT ARV Understanding	Yes	161	38%
	No	233	55%
	Missing	27	6%

Section 7: Attitude			
Variable	**Label**	**n=421**	**%**
Ok HIV positive woman pregnant?	Yes	25	6%
	No	396	94%
Ok man impregnate positive wife?	Yes	8	2%
	No	118	28%
	Missing	295	70%
Ok positive man impregnate positive wife?	Yes	12	3%
	No	282	67%
	Don't Know	1	0.2%
	Missing	126	30%
Ok negative man impregnate positive wife?	Yes	1	0.2%
	No	294	70%
	Missing	126	30%
Reasons ok for HIV+ women to give birth	If mother gets treatment	19	39%
	If have few/no children	9	18%
	Parent's choice	8	16%
Note: n=49 (includes all 4 questions, >1 response question allowed).	If mother is strong/healthy	4	8%
	Child may be HIV-	3	6%
	Other	6	12%
Reasons not ok for HIV+ women to give birth	Concern for mother	663	47%
	Concern for child	363	26%
Note: n=1404 (includes all 4 questions, >1 response question allowed).	Concern for father	320	23%
	Contrary to HCW advice	34	2%
	Other	24	2%

Section 8: VCT Counseling			
Variable	**Label**	**n=421**	**%**
MTCT discussed during VCT?	Yes	321	76%
	No	95	23%
	Don't Know	5	1%
FP discussed during VCT?	Yes	34	8%
	No	76	18%
	Yes, condoms only	99	24%
	Yes, condoms & other	207	49%
	Don't Know	5	1%

Appendix L – Univariate Analysis of Interview Data by HIV Status and Sex

	HIV Status			Sex		
Variable	**HIV+ (n=199)**	**HIV- (n=222)**	**p**	**Men (n=151)**	**Women (n=270)**	**p**
Recruitment Site*						
Rwimi	52% (103)	100% (222)	<0.001	80% (121)	76% (204)	0.0376
Bigodi	13% (26)	0% (0)		7% (10)	6% (16)	
Kibiito	35% (70)	0% (0)		13% (20)	19% (50)	
Age§	34.2 ± 6.0	27.8 ± 6.6	<0.001	33.7 ± 6.2	29.2 ± 7.0	<0.001
Sex *						
Female	61% (122)	67% (148)	0.025	N/A	N/A	N/A
Male	39% (77)	33% (74)				
Marital Status*						
Married	55% (109)	66% (145)	0.032	68% (101)	57% (153)	0.020
Cohabiting	45% (88)	34% (76)		32% (47)	43% (117)	
# Spouses*						
One	96% (191)	97% (215)	0.632	90% (136)	100% (270)	<0.001
Multiple	4% (8)	3% (7)		10% (15)	0% (0)	
Occupation*						
Farmer	66% (132)	83% (184)	<0.001	64% (97)	81% (219)	<0.001
Business	13% (26)	7% (15)		12% (18)	9% (23)	
Other	21% (41)	10% (23)		24% (36)	10% (28)	
Dwelling Floor*						
Cement/ concrete/wood	10% (19)	9% (20)	0.849	9% (13)	10% (26)	0.729
Mud	90% (180)	91% (202)		91% (138)	90% (244)	
Dwelling Walls*						
Permanent materials	9% (18)	12% (26)	0.372	8% (12)	10% (26)	0.209
Mud/ thatched	91% (181)	88% (196)		92% (138)	90% (244)	
Dwelling Roof*						
Metal	91% (182)	85% (188)	0.0330	90% (136)	87% (234)	0.305
Grass/ thatched	9% (17)	15% (34)		10% (15)	13% (36)	
Car Ownership*						
Yes	1% (1)	1% (2)	0.628	1% (1)	1% (2)	0.927
Radio Ownership*						
Yes	75% (149)	86% (192)	0.002	83% (126)	80% (215)	0.339
TV Ownership*						
Yes	1% (1)	2% (5)	0.130	1% (2)	1% (4)	0.896
Land Ownership*						
Yes	80% (159)	92% (204)	<0.001	87% (131)	86% (232)	0.813

Bicycle Ownership*						
Yes	33% (65)	50% (111)	<0.001	44% (67)	40% (109)	0.425
Animal Ownership*						
Yes	56% (112)	59% (130)	0.637	56% (85)	58% (157)	0.712
Poultry Ownership*						
Yes	62% (123)	77% (171)	0.001	69% (104)	70% (190)	0.748
Motorcycle Ownership*						
Yes	3% (6)	3% (7)	0.935	3% (5)	3% (8)	0.843
Attended School*						
Yes	82% (163)	85% (188)	0.445	93% (140)	78% (211)	<0.001
Education*						
None	18% (36)	15% (34)	0.805	7% (11)	22% (59)	<0.001
Lower Primary	31% (61)	32% (70)		30% (46)	31% (85)	
Upper Primary	37% (74)	41% (90)		41% (62)	38% (102)	
Lower Second. +	14% (28)	13% (28)		21% (32)	9% (24)	
Religion*						
Catholic	46% (92)	37% (83)	0.032	42% (64)	41% (111)	0.311
Protestant	38% (76)	36% (81)		39% (59)	36% (98)	
Muslim	4% (8)	10% (22)		4% (6)	9% (24)	
Other	12% (23)	16% (36)		14% (22)	14% (37)	
Religiosity*						
> once a week	24% (47)	15% (34)	0.089	19% (28)	20% (53)	0.221
Once a week	72% (144)	81% (180)		76% (114)	78% (210)	
< once a week	4% (8)	4% (8)		6% (9)	3% (7)	
Tribe* (n = 420)						
Mutooro	56% (112)	17% (38)	<0.001	37% (55)	35% (95)	0.185
Mukiga	28% (56)	46% (101)		41% (62)	35% (95)	
Mukonjo	2% (3)	20% (44)		11% (17)	11% (30)	
Other	14% (28)	17% (38)		11% (16)	19% (50)	
Pregnant* (n = 362)						
Yes	10% (14)	66% (142)	<0.001	24% (29)	53% (127)	<0.001
# Pregnancies§	4.9 ± 2.7	4.3 ± 2.6	0.0203	4.7 ± 2.7	4.5 ± 2.6	0.3906
Experienced Death of a Child?*						
Yes	40% (80)	41% (92)	0.796	35% (53)	44% (119)	0.072
# Living children§	4.0 ± 2.5	2.9 ± 2.2	<0.001	3.8 ± 2.5	3.2 ± 2.3	0.0226
Non-bio children?*						
Yes	59% (118)	34% (75)	<0.001	56% (85)	40% (108)	0.001
# Non-bio children§	1.3 ± 1.2	0.70 ± 1.1	<0.001	1.2 ± 1.3	0.81 ± 1.1	0.0006

Want children?* (n=420) Yes	14% (27)	53% (118)	<0.001	35% (52)	34% (93)	0.963
Want kids if neg instead of pos?* (n=115) Yes	57% (65)	N/A	N/A	53% (23)	58% (42)	0.612
How many kids if neg instead of pos§ (n=64)	2.3 ± 1.1	N/A	N/A	2.8 ± 1.4	1.9 ± 0.72	0.0088
# partner more kids§ (n=99)	1.7 ± 0.89	2.5 ± 1.5	0.0053	2.4 ± 1.5	2.4 ± 1.5	0.9945
Partner Discussion* (n=417) Yes No/Not with all	91% (180) 9% (17)	81% (178) 19% (42)	0.002	89% (133) 11% (16)	84% (225) 16% (43)	0.136
Fertility Decider* (n=416) Equal Participant Partner	79% (156) 14% (27) 7% (14)	65% (143) 23% (51) 11% (25)	0.007	76% (112) 20% (29) 5% (7)	70% (187) 18% (49) 12% (32)	0.054
# more kids desired§ (n=420)	0.22 ± 0.62	1.4 ± 1.6	<0.001	0.80 ± 1.2	0.84 ± 1.5	0.7527
Desired Children§	4.3 ± 2.4	4.9 ± 1.8	0.0025	4.8 ± 2.2	4.5 ± 2.1	0.2416
FP Ever Use* (n=418) Yes	86% (171)	47% (103)	<0.001	74% (111)	61% (163)	0.007
FP Current Use* (n=415) Yes	75% (148)	13% (28)	<0.001	53% (79)	36% (97)	0.001
FP Current Use-at risk only* (n = 292) Yes	79% (143)	40% (25)	<0.001	67% (75)	72% (93)	0.441
FP Current Use – effective methods* Yes	17% (34)	8% (18)	0.005	17% (25)	10% (27)	0.050
FP Current Use – effective methods and at risk* (n=296) Yes	19% (34)	27% (11)	0.168	22% (25)	20% (26)	0.761

FP Method* (n=175)						
OC Pill	4% (6)	15% (4)	<0.001	5% (4)	6% (6)	0.006
Injectables	7% (10)	41% (11)		15% (12)	9% (9)	
Male Condom	77% (114)	22% (6)		64% (50)	72% (70)	
Dual Method	5% (7)	4% (1)		10% (8)	0% (0)	
Other	7% (11)	19% (5)		5% (4)	12% (12)	
FP Use Prevented* (n=415)						
Yes	24% (47)	22% (49)	0.739	19% (29)	25% (67)	0.167
FP Covert Use* (n=98)						
Yes	2% (2)	9% (1)	0.218	N/A	3% (3)	N/A
HIV Status*						
Positive	N/A	N/A	N/A	51% (77)	45% (122)	
Negative				49% (74)	55% (148)	0.252
Partner HIV Status* (n=269)						
Positive	76% (118)	12% (14)	<0.001	42% (47)	54% (85)	0.049
Negative	24% (37)	88% (100)		58% (65)	46% (72)	
HIV test results received today*						
Yes	0.5% (1)	77% (171)	<0.001	22% (33)	51% (139)	<0.001
No	99.5% (198)	19% (43)		77% (116)	46% (125)	
Yes and No	0% (0)	4% (8)		1% (2)	2% (6)	
Status disclosure to partner* (n=246)						
Yes	96% (191)	100% (48)	0.186	97% (113)	97% (126)	0.817
No or not with all partners	4% (7)	0% (0)		3% (3)	3% (4)	
Testing disclosure to partner* (n=175)						
Yes	N/A	N/A	N/A	91% (32)	82% (115)	0.180
AIDS Death in Family* (n = 419)						
Yes	73% (144)	50% (112)	<0.001	65% (97)	59% (159)	0.263
AIDS Death of Child* (n=416)						
Yes	31% (61)	20% (44)	0.008	29% (44)	23% (61)	0.149

Impact of HIV diagnosis on RDM * (n = 420)						
Yes	52% (102)	59% (131)	0.223	53% (79)	57% (154)	0.010
No, Didn't make diff	6% (11)	6% (14)		11% (16)	3% (9)	
No, already decided to stop	43% (85)	35% (77)		37% (55)	40% (107)	
More, less, or stop* (n=233)						
More	1% (1)	0% (0)	0.473	0% (0)	1% (1)	0.379
Less	14% (14)	16% (21)		19% (15)	13% (20)	
Stop	85% (87)	110% (110)		81% (64)	86% (133)	
Childbearing timing changed* (n=38)						
Yes	67% (10)	83% (19)	0.259	60% (9)	87% (20)	0.056
Younger or older* (n=29)						
Younger	50% (5)	42% (8)	0.684	44% (4)	45% (9)	0.978
Older	50% (5)	58% (11)		56% (5)	55% (11)	
Discussion post diagnosis* (n=88)						
Yes	90% (79)	N/A	N/A	89% (33)	90% (46)	0.878
AIDS symptoms*						
Yes	65% (130)	0% (0)	<0.001	34% (52)	29% (78)	0.237
ARV treatment* (n=199)						
Yes	61% (122)	0% (0)	<0.001	34% (51)	26% (71)	0.105
Pregnant post diagnosis* (n=199)						
Yes	8% (15)	N/A	N/A	5% (4)	9% (11)	0.320
Pregnancy planned* (n=15)						
Yes	7% (1)	N/A	N/A	0% (0)	9% (1)	0.533
PMTCT* (n=15)						
Yes	67% (10)	N/A	N/A	75% (3)	64% (7)	0.680
HCW disclosure* (n=10)						
Yes	100% (10)	N/A	N/A	100% (3)	100% (7)	N/A
Treated differently* (n=10)						
Yes	30% (10)	N/A	N/A	0% (0)	43% (3)	0.175

MTCT no ARVs* (n=71)								
Yes		94% (50)	100% (18)	0.303		89% (25)	100% (43)	0.028
# MTCT no ARVs§ (n=63)		6.3 ± 3.0	7.30 ± 2.72	0.2177		6.1 ± 3.4	6.8 ± 2.5	0.3992
MTCT ARVs* (n = 70)								
Yes		43% (23)	47% (8)	0.791		52% (14)	39% (17)	0.313
# MTCT ARVs§ (n=66)		2.0 ± 2.9	2.5 ± 3.6	0.6290		2.0 ± 2.7	2.2 ± 3.3	0.7645
MTCT possible* (n=408)								
Yes		96% (185)	97% (209)	0.453		95% (138)	98% (256)	0.090
MTCT village birth no ARVs* (n = 324)								
Yes		100% (135)	100% (189)	N/A		100% (113)	100% (211)	N/A
# MTCT village birth no ARVs§ (n = 292)		9.0 ± 1.7	8.9 ± 1.7	0.4445		8.8 ± 1.8	9.0 ± 1.7	0.3883
MTCT hospital birth no ARVs* (n = 318)								
Yes		50% (65)	47% (88)	0.575		52% (57)	46% (96)	0.281
# MTCT hospital birth no ARVs§ (n = 304)		3.0 ± 3.7	2.9 ± 3.7	0.9143		3.1 ± 3.6	2.9 ± 3.7	0.6540
MTCT village birth ARVs* (n =292)								
Yes		74% (87)	63% (109)	0.048		75% (76)	63% (120)	0.049
# MTCT village birth ARVs§ (n = 272)		5.6 ± 4.1	4.5 ± 4.2	0.0433		5.6 ± 4.1	4.6 ± 4.1	0.0545
MTCT hospital birth ARVs* (n = 298)								
Yes		14% (17)	11% (20)	0.537		17% (18)	10% (19)	0.054
# MTCT hospital birth ARVs§		0.57 ± 1.8	0.47 ± 1.6	0.6183		0.72 ± 2.0	0.40 ± 1.5	0.1418
MTCT Understanding *								
Low		72% (143)	74% (164)	0.642		66% (99)	77% (208)	0.011
High		28% (56)	26% (58)			34% (52)	23% (62)	

MTCT Risk Understanding * (n=394) Yes		63% (117)	56% (118)	0.171		64% (88)	57% (147)	0.221
MTCT ARV Understanding * (n=394) Yes		45% (84)	37% (77)	0.084		38% (52)	43% (109)	0.346
Ok HIV positive woman pregnant?* Yes		6% (11)	6% (14)	0.736		6% (10)	6% (15)	0.657
Ok man impregnate positive wife?* (n=126) Yes		6% (5)	6% (3)	0.990		9% (5)	4% (3)	0.226
Ok positive man impregnate positive wife?* (n = 294) Yes		3% (3)	5% (9)	0.255		5% (5)	4% (7)	0.532
Ok negative man impregnate positive wife?* (n=295) Yes		0% (0)	1% (1)	0.407		0% (0)	1% (1)	0.480
Attitude – ok pos people pregnant* Yes		7% (14)	7% (15)	0.910		8% (12)	6% (17)	0.521
MTCT discussed during VCT?* (n = 416) Yes		83% (165)	72% (156)	0.004		82% (121)	75% (200)	0.097
FP discussed during VCT?* (n = 416) Yes		93% (184)	71% (156)	<0.001		90% (133)	77% (207)	0.001

[a] n=421 unless otherwise indicated

* indicates a categorical variable on which a chi-squared test was performed

§ indicates a continuous variable on which a t-test was performed (mean ± SD reported)